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**‘This is my life and I’m going to live it’: A grounded
theory approach to conceptualising resilience in
people with mild to moderate dementia**

Gillian Bailey

*Submitted in part fulfilment of the degree of Doctorate in Clinical
Psychology at the University of Edinburgh*

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Dedication

In memory of my father

Acknowledgements

Firstly, thank you to those who agreed to participate in my study and share their experiences. It was a great privilege to listen, learn, and be inspired by them. I would also like to thank those members of the Older Adult Community Mental Health Teams in NHS Forth Valley who helped to make this study possible.

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Thesis abstract

Background: Interest in resilience has rapidly increased over recent years because of its potential impact on health, well-being and quality of life. However, despite the increasing prevalence of dementia, there is a lack of resilience research involving people diagnosed with this condition. Therefore, little is known about what it is that enables people to live well with dementia and continue to lead successful and meaningful lives. Even small delays in the onset and progression of dementia have the potential to significantly reduce its global burden. More specifically, studies have shown an association between social engagement and reduced risk of cognitive decline and incident dementia and consequently there is growing interest in the effect of increasing social interaction on cognition.

Objectives: This thesis comprises two parts. Initially, a systematic literature review summarises and evaluates the current empirical evidence to establish whether interventions which aim to increase social interaction can improve cognition in older adults. Secondly, a qualitative study aims to develop a grounded theory of the concept of resilience in people diagnosed with mild to moderate dementia.

Methods: For the systematic review, a comprehensive list of electronic databases was systematically searched, relevant authors in the field were contacted and a hand search of relevant journals was conducted. For the qualitative study, seven semi-structured interviews were conducted with people diagnosed with dementia, with a social constructivist version of grounded theory informing the collection and analysis of data.

Results: 17 studies met eligibility criteria for the systematic review, mostly of moderate quality. Study heterogeneity and methodological variability made it difficult to determine

the specific contribution of social interaction to cognitive improvements. There was, however, tentative support for improvement in semantic fluency. The results of the qualitative study propose a model which hypothesises resilience is a process of '*overcoming dementia*'. For participants this meant maintaining a sense of pre- and post-diagnostic continuity which was achieved through a complex interaction of their approach to life and acceptance of dementia in conjunction with spousal and other social support.

Conclusions: Although the systematic review found some evidence increased social interaction can improve cognition in older adults, this finding is tentative and should be interpreted with caution, with further research warranted. The qualitative study proposes a model of resilience which explains the process of '*overcoming dementia*'. Resilience is conceptualised as comprising individual, social, community, societal and cultural aspects and opens up the possibility of promoting resilience in people with dementia through the development of psychosocial interventions. This study emphasises the strengths and abilities of people with dementia, as well as the importance of social support, but most importantly it is from the perspective of the person with dementia.

Systematic Review

The effect of social interaction on the cognition of older adults: A systematic review

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(excluding abstract, tables and references)*

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(Prepared in accordance with guidelines for the journal '*Dementia*', see Appendix 1. Please note tables and figures have been included in the text in line with the university rather than journal requirements).

Systematic review abstract

Background: Studies have shown an association between social engagement and reduced risk of cognitive decline and incident dementia. Interest has grown in interventions which increase social interaction in older adults and their effect on cognition.

Objectives: To systematically review and evaluate the current empirical evidence for improvement in cognitive function in older adults as a consequence of interventions which increase social interaction.

Methods: A comprehensive list of electronic databases was systematically searched, relevant authors in the field were contacted and a hand search of relevant journals was conducted.

Results: 17 studies met eligibility criteria, mostly of moderate quality. Study heterogeneity and methodological variability made it difficult to determine the specific contribution of social interaction to cognitive improvements. There was, however, tentative support for improvement in semantic fluency.

Conclusions: Further research is warranted to determine the contribution of increasing social interaction on cognitive outcomes in older adults and the underlying mechanisms.

Keywords: cognition, dementia, older adults, social interaction, systematic review.

Word count: 150

Introduction

An ageing population has resulted in an unprecedented increase in the number of older people in society along with an exponential increase in the number of older adults experiencing cognitive decline and dementia, including Alzheimer's disease. There are over 44 million people worldwide with dementia, with this figure predicted to increase to over 75 million by 2030 (Prince et al., 2013). The associated costs to individuals, families and governments are immense with the current annual financial cost of dementia in the UK alone estimated to be in excess of £26 billion (Prince et al., 2014). The potential benefit of preventative and therapeutic strategies is huge. Brookmeyer, Johnson, Ziegler-Graham, & Arrighi (2007) suggest even modest advances leading to small delays in the onset and progression of Alzheimer's disease could significantly reduce its global burden.

Sustained engagement in social activities is considered an important aspect of successful ageing (Rowe & Kahn, 1997). Studies have shown people who have access to more social connections have reduced levels of morbidity (Boden-Albala, Litwak, Elkind, Rundek, & Sacco, 2005; Ell, Nishimoto, Mediansky, Mantell, & Hamovitch, 1992; Everson-Rose & Lewis, 2005) and mortality (Berkman & Syme, 1979; House, Umberson, & Landis, 1988). A meta-analytic review of 148 studies providing data concerning the mortality of individuals as a function of social relationships, which included both structural and functional aspects, reported a 50% increased likelihood of increased survival for those with stronger social relationships. They concluded the influence of social relationships on risk of mortality is comparable to, or exceeds, other well-established risk factors such as smoking, obesity and physical inactivity (Holt-Lunstad, Smith, & Layton, 2010).

Interest has grown in the role of social protective factors for cognitive decline and the development of dementia along with the availability of results from observational longitudinal cohort studies. These suggest social engagement (Barnes, Mendes de Leon, Wilson, Bienias, & Evans, 2004; Beland, Zunzunegui, Alvarado, Otero, & del Ser, 2005 ; Zunzunegui, Alvarado, Del Ser, & Otero, 2003), social support (Arbuckle, Gold, Andres, Schwartzman, & Chaikelson, 1992), social network (Crooks, Lubben, Petitti, Little, & Chiu, 2008; Holtzman et al., 2004), social contact (Elwood et al., 1999), and social activities (Wang, Karp, Winblad, & Fratiglioni, 2002) have a protective effect on cognition. With an absence of social ties increasing the risk of cognitive impairment (Bassuk, Glass, & Berkman, 1999). Although some studies failed to find an association (Albert, Jones, Savage, Berkman, & al, 1995; Hertzog, Hultsch, & Dixon, 1999; Yoshitake et al., 1995).

An association has been reported between decreased social networks and higher risk of incident dementia (Crooks et al., 2008; Fratiglioni, Wang, Ericsson, Maytan, & Winblad, 2000; Saczynski et al., 2006), with greater social participation being linked to lower dementia incidence (Fabrigoule et al., 1995; Fratiglioni, Paillard-Borg, & Winblad, 2004; Karp et al., 2006; Scarmeas, Levy, Tang, Manly, & Stern, 2001; Wang et al., 2002). While other observational studies suggest dissatisfaction with social contacts is a risk factor. Frataglioni and colleagues (2000) found people with infrequent contacts with their social network resources were not at increased risk if they experienced those contacts as satisfying. Similarly, Amieva and colleagues (2010) studied both structural characteristics of social networks and quality of relationships. They found only variables reflecting quality, such as low satisfaction, were associated with subsequent risk of developing dementia. In addition, frequent but unsatisfying contact with children has been related to increased risk (Fratiglioni et al., 2000). Further research found the only social variable associated to higher risk was

the absence of a confidant (Camozzato et al., 2015). Moreover, studies found perceived social isolation, or loneliness, rather than actual social isolation is associated with increased risk (Holwerda et al., 2012; Wilson et al., 2007) while a recent interventional study found the cognition of lonely older people was significantly improved by taking part in a socially stimulating group for three months (Pitkala, Routasalo, Kautiainen, Sintonen, & Tilvis, 2011).

Reviews investigating the influence of social factors and risk of dementia, including social activities, social engagement and a socially integrated lifestyle, have been inconclusive in their findings (Di Marco et al., 2014; Fratiglioni et al., 2004; Wang, Xu, & Pei, 2012; Pillai & Verghese, 2009; Williams, Plassman, Holsinger, & Benjamin, 2010). More recently a systematic review and meta-analysis of 19 longitudinal cohort studies, conducted by Kuiper and colleagues (2015), found reduced social participation, less frequent social contact and increased feelings of loneliness were associated with an increased risk. They reported it is social relationship factors representing a lack of social interaction which are associated with incident dementia more so than the size or satisfaction with social network. In addition, they concluded the strength of the association between poor social interaction and incident dementia is commensurate to that of other well-established risk factors for dementia, such as late-life depression, physical inactivity and low education attainment.

Although these findings may seem compelling, it is possible the premorbid cognitive capability of individuals to engage socially might mediate or confound reported associations. Observational longitudinal studies do not demonstrate causality and it is possible reduced social engagement, activity, and network may represent prodromal cognitive and depressive symptoms that have been reported in the early phases of dementia (Fratiglioni et al., 2004) and the protective effect of social factors is merely an epiphenomenon (Pillai & Verghese, 2009). Saczynski and colleagues (2006) found people whose social engagement was

consistently high, or consistently low, were at lower risk of developing dementia than those whose social engagement changed at midlife from high to low, supporting reverse causation. In a recent study involving long-term follow-up of up to 16 years Sörman, Rönnlund, Sundström, Adolfsson and Nilsson (2015) found that when participants with a survival time of fewer than three years were excluded from their analyses, all of the previous associations between social factors and incident dementia disappeared, leading them to conclude they may have been driven by reverse causality. In addition to observational longitudinal studies, randomised controlled trials (RCTs) are considered the “gold standard” to investigate a causal relationship between social factors and cognitive decline (Wang et al., 2012).

Aim

The aim of this systematic review is to evaluate and summarise the current empirical evidence to establish whether interventions which aim to increase social interaction can improve cognition in older adults.

Methods

A systematic search of the literature was conducted to identify studies of interventions which aimed to increase social interaction in older adults.

Search strategy

Literature searches were conducted in September 2015 and were informed by guidance from the Centre for Reviews and Dissemination on undertaking reviews in health care (Centre for Reviews and Dissemination, 2009), Hammerstrøm, Wade, & Jørgensen (2009) and Petticrew & Roberts (2006). The electronic databases searched included Applied Social Sciences Index

and Abstracts (ASSIA), the Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus), Embase, Ovid MEDLINE, psycINFO, and Social Services Abstracts. The searches were conducted without date limits to maximise sourcing relevant papers. The search strategy involved defining search terms which were refined and grouped into four categories as outlined below:

1. (older adult* OR late* life OR elder* OR senior* OR geriatric)

AND

2. (social interaction* OR social* stimulat* OR social relationship* OR social network* OR social isolation OR socialising OR socializing OR social support OR loneliness OR interpersonal OR social engagement)

AND

3. (cognition OR cognitive performance OR cognitive function* OR cognitive decline OR cognitive impairment OR executive function* OR memory)

AND

4. (RCT OR feasibility OR pilot OR intervention OR trial*)

Manual searches were conducted of review, and other relevant article reference lists, and key journals (*Ageing and Society*, *Alzheimer's and Dementia*, *Cognitive Psychology*, *Psychology and Aging* and *The Gerontologist*), which resulted in the inclusion of six further papers. Attempts were made to identify further studies by contacting the first authors of review articles and other relevant sources. In total 19 authors were contacted, with 13 of those responding, with no further articles being identified.

Selection criteria

Inclusion criteria for the purposes of the review were:

- Studies which describe interventions which aim to increase social interaction.
- Participants are aged ≥ 60 years.
- Studies include a pre- and post-intervention measure of cognition.
- Participants who are cognitively intact or have mild impairment (Mini-Mental State Examination; MMSE ≥ 24 , or education adjusted equivalent, or equivalent where alternative assessment tool is used), including a diagnosis of mild cognitive impairment (MCI).
- Studies published in English.

Exclusion criteria for the purposes of this review:

- Studies which include participants selected from specific populations: individuals with pre-existing chronic or acute health conditions (e.g. dementia, Parkinson's disease, stroke, heart disease, cancer, traumatic brain injury, multiple sclerosis, etc.); individuals with pre-existing chronic or acute mental illness (e.g. depression, anxiety, post-traumatic stress disorder, psychosis, etc.).
- Participants who have moderate or severe cognitive impairment (MMSE < 24 , or education adjusted equivalent, or equivalent where alternative assessment tool is used).
- Reviews, theoretical articles, methodological protocols, case studies, conference abstracts, dissertations.

Quality criteria

When considering quality assessment a number of existing guidelines and checklists were consulted, including Cochrane Handbook for Systematic Reviews of Interventions (Cochrane, 2011) and the Scottish Intercollegiate Guidelines Network, (SIGN 50, 2014) as well as Deeks and colleagues' (2003) systematic review on evaluating non-randomised intervention studies. As the eligibility criteria allowed for the inclusion of different study designs the Downs and Black checklist (Downs & Black, 1998), which was developed to assess the quality of both randomised and non-randomised studies, was used (See Appendix 2.). In their review, Deeks and colleague (2003) identified 182 instruments for assessing methodological quality, which they shortlisted to 14, identifying six as potentially useful for systematic reviews, with the Downs and Black checklist identified as one of the two most useful (Cochrane, 2011).

The Downs and Black checklist comprises 27 questions divided into five subscales: Reporting, External Validity, Internal Validity (bias), Internal Validity (confounding) and Power. Scores on the original tool ranged from zero to 32, with a higher score indicating superior methodological quality. As in previous reviews (Eng et al., 2007; Searle, Spink, Ho, & Chuter, 2015; Xiao et al., 2014), question 27 was modified from a scale of zero to five to a score of zero or one depending on whether the study reported a power or sample size calculation. Therefore, the scores possible on the modified checklist ranged from zero to 28. For the purpose of this review the Down's and Black's scores were grouped into the following four quality levels: "excellent" ($\geq 90\%$), "good" ($\geq 70\%$), "moderate" ($\geq 50\%$) and "low" ($< 50\%$).

Results

Study selection

The study selection procedure is outlined in Figure 1., based on the PRISMA statement (Moher, Liberati, Tetzlaff, & Altman, 2009). The database searches resulted in the retrieval of 1537 potentially relevant studies, with 1183 remaining on the removal of duplicates. Screening of titles and abstracts for suitability according to the inclusion and exclusion criteria resulted in 1101 studies being excluded. The remaining 82 studies were accessed in full, with 11 being retained for inclusion in the review (Carlson et al., 2008; Carlson et al., 2009; Cohen-Mansfield et al., 2014; Dannhauser et al., 2014; Kamegaya, Araki, Kigure, & Yamaguchi, 2014; Kamegaya et al., 2012; Li et al., 2014; Maki et al., 2012; Mortimer et al., 2012; Noice & Noice, 2006; Stine-Morrow et al., 2014). A further six studies were identified from additional sources (Dodge et al., 2015; Kattenstroth, Kalisch, Holt, Tegenthoff, & Dinse, 2013; Noice & Noice, 2009; Noice & Noice, 2013; Noice, Noice, Perrig-Chiello, & Perrig, 1999; Noice, Noice, & Staines, 2004) thus bringing the total number of included articles to 17. Given the limited amount of research in this area, no studies were excluded based on quality.

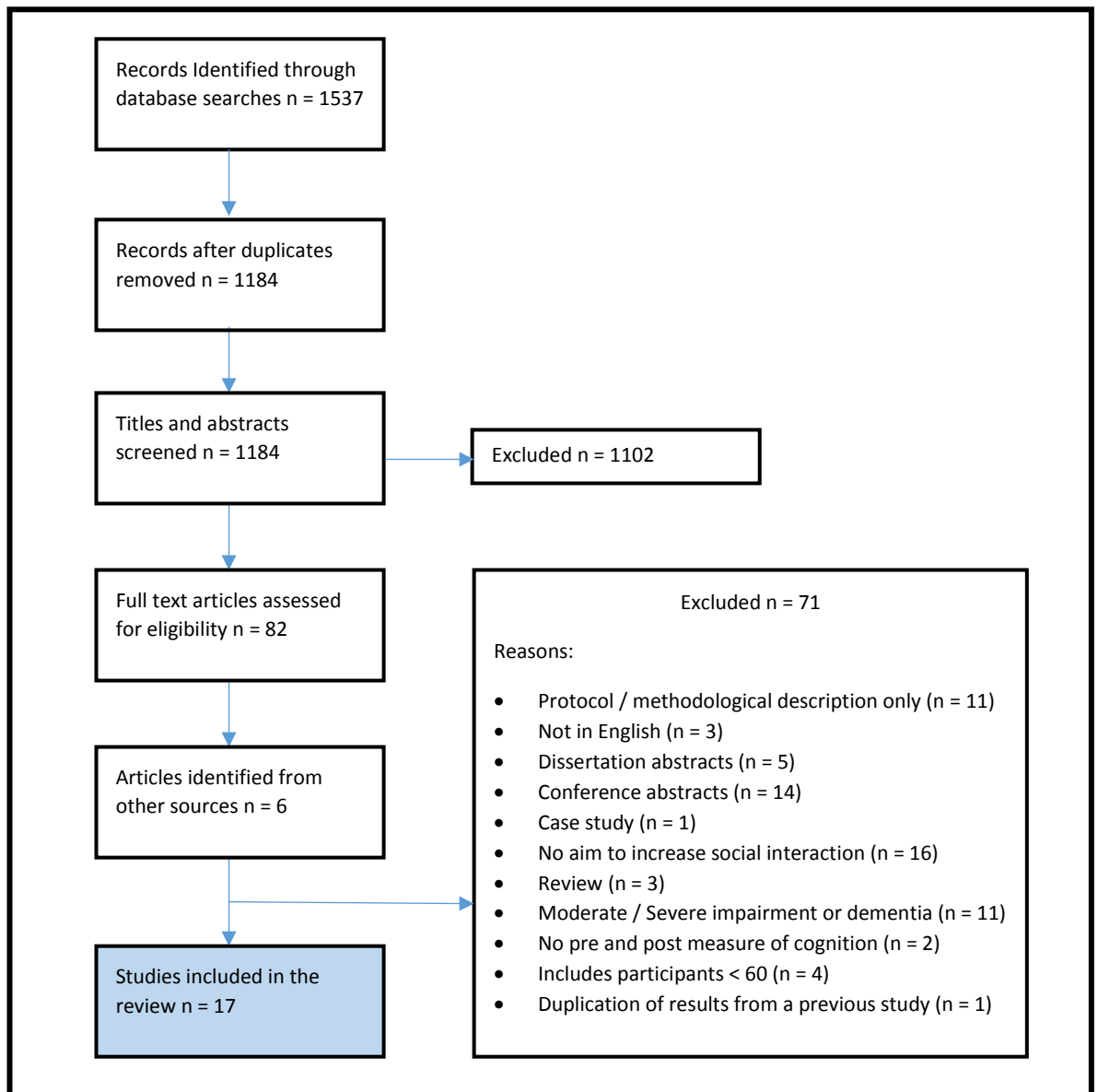


Figure 1. Study selection procedure

Data Extraction

The following data was extracted, using a bespoke form (Appendix 3.), to summarise the relevant information from each of the included studies: *location, gender, age, years of education, baseline cognitive functioning, intervention details, intervention duration, cognitive outcome measures, design, follow-up and relevant results.*

Study characteristics

The studies included in this review (see Table 1.) comprise 10 RCT's (Carlson et al., 2008; Cohen-Mansfield et al., 2014; Dodge et al., 2015; Kamegaya et al., 2014; Kattenstroth et al., 2013; Maki et al., 2012; Mortimer et al., 2012; Noice & Noice, 2009; Noice & Noice, 2013; Stine-Morrow et al., 2014), six controlled trials (Carlson et al., 2009; Dannhauser et al., 2014; Kamegaya et al., 2012; Li et al., 2014; Noice et al., 2004; Noice & Noice, 2006) and one non-controlled trial (Noice et al., 1999). The studies were published between 1999 and 2015 and were conducted in a variety of locations: eight studies in the United States of America, three in Japan, two in China, and one in Germany, Israel, Switzerland and the United Kingdom. The number of participants per study ranged from 13 (Noice et al., 1999) to 461 (Stine-Morrow et al., 2014), with a total of 1670 participants. The participants in the studies were predominantly female, ranging from 67% to 100% apart from two studies (Dannhauser et al., 2014; Li et al., 2014) where the proportion of female participants was 41% and 42%, one did not report gender. All studies, apart from one, reported the mean age of participants. In 12 studies the mean age of participants was between 67 and 75 years and in the other four studies the mean age was between 80 and 84 years. Where reported, the number of years of education varied from a mean of fewer than nine years (Kattenstroth et al., 2013) to greater than 15 years (Stine-Morrow et al., 2014). The majority of participants were community-dwelling older adults, with participants in three studies residing in specialist older adult facilities with varying levels of care provision (Noice & Noice, 2006; Noice & Noice, 2009; Noice & Noice, 2013). The baseline cognitive functioning of participants varied across studies. Where the MMSE score was reported they varied from a mean of 24.5 to 28.7, with some studies specifying the inclusion of some (Dodge et al., 2015; Kamegaya et al., 2012; Kamegaya et al., 2014) or all participants with a diagnosis of MCI (Dannhauser et al., 2014).

Only two of the studies conducted a follow-up assessment (Noice & Noice, 2014; Dodge et al., 2015).

Nine of the studies were described as community-based interventions (Carlson et al., 2008 & 2009; Dannhauser et al., 2014; Kamegaya, et al., 2012 & 2014; Maki et al., 2012; Mortimer et al., 2012; Noice & Noice, 2004; Stine-Morrow et al., 2014). Five were based on the same theatrical intervention (Noice et al., 1999; Noice et al., 2004; Noice & Noice, 2006; Noice & Noice, 2009; Noice & Noice, 2013) and both studies by Carlson and colleagues (2008, 2009) were based on the Experience Corps® intervention, otherwise interventions were diverse and duration ranged from four weeks to eight months. Most interventions could be considered multi-modal with only two studies including conditions focussing solely on increasing social interaction (Dodge et al., 2015; Mortimer et al., 2012). Due to the heterogeneity of the studies, particularly in relation to intervention, outcome measures, and participants meta-analytic synthesis was not appropriate and a narrative synthesis was conducted (Petticrew & Roberts, 2006).

Table 1. Description of review studies

| Study | Location | N/ Female, % | Mean baseline age (SD), range | Education (years) | Baseline cognitive functioning (MMSE, SD) | Intervention | Duration | Cognitive outcome measures | Design/ follow-up | Results relevant to research question |
|--------------------------------------|----------|-----------------|--|--|---|---|------------------|---|---|--|
| Randomised Controlled Trials | | | | | | | | | | |
| Carlson et al. (2008) | USA | 149 90% | EC group: 70.1 (6.42) CG: 68.4 (5.15) 60+ | EC group: 11.9 (2.54) CG: 11.2 (2.66) | EC group: 24.96 (3.45) CG: 25.3 (2.60) | EC programme – volunteer senior service in elementary schools. 15 hours per week during the academic year. | 4 to 8 months | Memory: Word list immediate and delayed Visuospatial: Rey-Osterrieth CFT(delayed) EF: TMT-B Rey-Osterrieth CFT(copy) Psychomotor speed: TMT A | RCT- 2 treatment arms: EC and waitlist control Pre-post measures: no follow-up | EC group showed improvements in EF and memory compared with control group. EC group improved and CG deteriorated on TMT B and CFT. The difference between executive function impaired groups on TMT-B and word list delayed was significant ($p < .05$). The group difference on the CFT delayed recall was marginally significant ($p = .05$). EC participants with impaired baseline EF showed intervention specific gains on all tests, except TMT A. Participants in the unimpaired EF and CG showed no appreciable changes. |
| Cohen- Mansfield et al. (2015) | Israel | 44 73% | Cognitive Training: 72.80 (3.78) Health promotion: 74.44 (5.78) PC: 73.21 (5.97) 60+ | Cognitive Training: 14.25 (4.18) Health promotion: 14.50 (4.17) PC: 14.50 (4.17) | Cognitive Training: 27.93 (1.82) Health promotion: 28.67 (1.05) PC: 28.93 (1.07) | Cognitive training course- memory training based on the ACTIVE course. Health promotion course – structured classes consisting of lectures discussions and exercises. Participation-centred course - memory, cognitive, and organisational strategies delivered within a book club context promoting social engagement | 10 weeks | Global cognition: MMSE and GCS(five domains - memory, executive function, visual spatial, attention) | RCT – 4 treatment arms: Cognitive training, Health promotion, Participation- centred and a wait-list control. Pre-post measure data collected at T0, T1 and T2 : no follow-up | All three interventions resulted in significant improvement in cognitive function as measured by the GCS ($p =$.001), with no significant difference between the interventions. No differential effect on cognitive domains by group was found. |

| | | | | | | | | | | |
|------------------------|-------|---------------|---|--|--------------------------------------|--|----------|--|--|---|
| Dodge et al. (2015) | USA | 83 76% | IG: 80.9 (7.2) CG: 80.2 (6.6) 65+ | NR 96.4% IG and 95.2% CG completed high school or greater | IG: 28.2 (1.7) CG: 28.3 (1.8) | IG engaged in 30-minute face-to-face communications with trained interviewers 5 days per week for 6 weeks by way of a video chat-enabled PC. CG received weekly telephone calls to assess social engagement activities during the previous week. | 6 weeks | Memory: Immediate -CEARD word list learning Delayed - CEARD word list delayed recall Working - COGSTATE one back and two back Verbal fluency: Category fluency Letter fluency Psychomotor Speed: TMT-A, COGSTATE detection test EF: TMT B SA/Inhibition: Stroop test. | RCT – 2 treatment arms: IG and CG Pre-post measures: 12 weeks follow-up | Category fluency scores improved significantly more in the IG than in the CG ($p < .05$). This effect came mainly from the cognitively intact participants ($p < .005$). At follow-up, the category fluency scores no longer differed between the two groups. At follow-up letter fluency scores showed greater improvement among cognitively intact participants in the IG ($p < .005$). Although both groups had similar levels of improvement/learning effects at the post-trial assessment, the letter fluency scores had improved further in the IG after the end of the trial sessions whilst declining in the CG. |
| Kamegaya et al. (2014) | Japan | 52 90% | IG: 73.6 (5.6) CG: 76.2 (6.1) 65 - 87 | IG: 11.6 (2.0) CG: 11.2 (2.4) | IG: 27.6 (2.0) CG: 27.9 (1.6) | Comprehensive 2-hour weekly programme of physical and leisure activities aimed at enhancing participants' motivation to participate and support one another by providing a pleasant atmosphere, empathetic communication, praise, and support. CG did not attend a programme. | 12 weeks | 5-Cog test consisting of character position referencing (attention), cued recall (memory), clock drawing (visuospatial functioning), category fluency (verbal fluency), analogy (abstract reasoning) EF: WDSST and YKSST | RCT – 2 treatment arms: IG and CG Pre-post measures: no follow up | The IG had a significant increase in the score on the Five-Cog test's analogy task relative to the control group ($p < .05$). |

| | | | | | | | | | | |
|----------------------------|---------|--------------------------|--|--|--|--|----------|---|---|--|
| Kattenstroth et al. (2013) | Germany | 35 IG: 68% CG: 70% | IG: 68.6 (1.45) CG: 72.3 (1.84) 60 - 94 | IG: 10.55 (0.38) CG: 8.89 (0.56) | MMSE scores from 27 to 30 | IG – professional dance class (Agilando) for 1.5 hours per week CG – no intervention | 6 months | Cognitive performance/neuropsychological status: RBANS(12 subsets) Selective attention/ concentration: AKT, FAIR Non-verbal learning: NVLT | RCT – 2 treatment arms: IG and CG Pre-post measures: no follow up | The IG showed a significant improvement on RBANS ($p \leq .001$, FAIR (errors; $p < .05$), Fair (signs; $< .01$, NVLT (geometric item, correct YES response; ($p < .05$) with no difference found in CG. |
| Maki et al. (2012) | Japan | 150 71% | Walking group: 71.9 (4.1) CG: 72.0 (3.9) 65+ | Walking group: 11.8 (2.5) CG: 11.9 (2.3) | Walking group: 27.7 (1.9) CG: 27.9 (2.0) | A walking programme conducted weekly for 90 minutes over 3 months in small groups and participant planned walking events (excursions). Combined benefit of exercise and social interaction expected. CG received educational healthcare lectures which were not directly related to preventing cognitive decline. | 3 months | 5-Cog test consisting of character position referencing (attention), cued recall (memory), clock drawing (visuospatial functioning), category fluency (verbal fluency), analogy (abstract reasoning) Sustained attention: WDSST and YKSST EF: TMT-B Psychomotor speed: TMT A | RCT - 2 treatment arms: walking group and CG Pre-post measures: no follow-up | Category fluency scores of participants in the walking group improved significantly more than those in the CG ($p < .05$). There were no significant differences in other tests. |
| Mortimer et al. (2012) | China | 120 67% | Tai Chi group: 67.3 (5.3) Walking group: 67.8 (3.9) Social interaction group: 67.9 (6.5) | Tai Chi group: 11.8 (2.6) Walking group: 10.9 (3.9) Social interaction group: 11.4 (3.3) | NR (MMSE < 26 excluded) MDRS: Tai Chi group: 134.6 (6.0) | Tai Chi (non-aerobic), Walking (aerobic), and social interaction (discussion) groups met three 3 times per week for 40 weeks. Participants in the no intervention group were contacted by telephone 4 times during the 40 weeks to prevent dropout. | 40 weeks | Global cognition: MDRS (5 subscales-attention, initiation, construction, conceptualisation, memory) Memory: CAVLT, digit span Rey-Osterrieth CFT(delayed) Verbal fluency: Category fluency | RCT - 4 treatment arms: Tai Chi, Walking, Social interaction and control Pre-mid-post measures: no follow-up | Compared with control group the Tai Chi group showed significant improvements on the MDRS total score ($p < 0.01$), and several components including the Initiation score ($p < 0.01$), Attention score ($p < 0.05$), and Memory score ($p < 0.05$). TMT-A and B (both $p < 0.01$), delayed recognition on the CAVLT ($p = < 0.01$), category fluency ($p < 0.05$). |

| | | | | | | | | | | |
|----------------------|-----|--|---|---|---|--|---------|--|---|---|
| | | | CG: 12.5 (3.8) 60 -79 | CG: 12.5 (3.8) | Walking group: 137.3 (11.2) Social interaction group: 138.5 (7.9) CG: 140.0 (5.4) | | | EF: TMT-B Rey-Osterrieth CFT(copy) Psychomotor speed: TMT A SA/Inhibition Stroop Test Visuospatial functioning: BCT Clock-drawing test, Rey-Osterrieth CFT Verbal comprehension: WAIS-R Similarities Test Language: BNT | | The Social Interaction group showed a trend for improvement ($p < 0.10$) on time to complete TMT-A and immediate recall on the CVLT and a significant improvement on category fluency ($p < 0.05$) when compared to CG. No significant effects or trends were observed in the Walking group as a whole when compared with the CG. |
| Noice & Noice (2009) | USA | 137 Theatre: 80.2% Music: 82.7% CG: 81.6% | 81.7 (5.8) 68-93 | 12.7 (2.04) | NR Screened using SPMSQ to exclude those without intact cognitive functioning | Theatre training -twice-weekly one-hour sessions of instruction in professional acting techniques, which did not involve intentional memorising of scripts. Music course - twice-weekly one-hour sessions of instruction in singing. CG – no treatment | 4 weeks | Memory: Word list (immediate and delayed), digit span (forwards and backwards), EBMT (immediate and delayed) Verbal fluency: Category fluency Problem-solving: MEPSP | RCT - 3 treatment arms: theatre group, music group, and CG Pre-post measures: no follow-up | It was found that the acting group improved significantly from pre-test to post-test over both other groups on immediate word list recall ($p < .001$), delayed word list recall ($p < .05$), category fluency ($p < .001$), delayed EBMT ($p < .05$), MEPSP ($p < .001$) Results for digit span (forwards and backwards) and immediate EBMT were not significant. |
| Noice & Noice (2013) | USA | EXPT 1 78 Theatre: 78.9% CG: 85.7% | EXPT 1 Theatre: 84.11 (4.39) CG: 83.25(6.53) 68-94 | EXPT 1 Theatre: 13.93(1.89) CG: 14.14 (2.75) | NR Screened using SPMSQ to exclude those without intact cognitive functioning | Theatre training 1 -twice-weekly 70-minute sessions of instruction in professional acting techniques, which did not involve intentional memorising of scripts, taught by in-house activity director. CG- waitlist control | 4 weeks | Memory: Word list (immediate and delayed), digit span (forwards and backwards), EBMT (immediate and delayed) Verbal fluency: Category fluency Problem-solving: MEPSP | RCT - 2 treatment arms: theatre group and CG Pre-post measures: no follow-up | EXPT 1 Experiment 1 showed that activity directors were able to run this intervention and significant results were found on one cognitive measure, MEPSP ($p < .05$). |

| | | | | | | | | | | |
|----------------------------|-----|--|---|--|--|--|---|--|--|--|
| | | EXPT 2 37 Theatre: 76% CG: 79% | EXPT 2 Theatre: 80.8(7.1) CG: 81.0(5.6) NR | EXPT 2 Theatre: 14.4(2.2) CG: 14.8(3.4) | | EXPT 2 Theatre training 2-twice-weekly 70-minute sessions of instruction in professional acting techniques, which did not involve intentional memorising of scripts, taught by the professional acting teacher. CG – waitlist control | | | | EXPT 2 Experiment 2 showed that outside acting teachers were able to run this intervention and significant results were found on immediate word recall ($p < .001$), MEPSP ($p < .001$), and category fluency ($p < .05$) |
| Stine-Morrow et al. (2014) | USA | 461 EG: 71% Training: 77% CG: 76% | EG: 71.7 (8.0) Training: 73.4 (7.5) CG: 72.9 (7.4) 60-94 | EG: 15.7 (2.6) Training: 15.2 (2.7) CG: 15.4 (2.5) | NR MoCA: EG: 26 (2.9) Training: 26.1 (3.0) CG: 25.9 (3.0) | Odyssey of the Mind programme – engagement programme designed to build skills in creative problem solving within a rich and stimulating environment. Weekly 1.5 hr meetings, total of 15 hr Odyssey activities per week Training: home-based instruction in inductive reasoning. 10 weekly lessons supplemented with puzzles to equate duration of Training with EG | 16 programme weeks that were spread from autumn into spring | Processing speed: Letter and Pattern Comparison and Finding A's task Reasoning: Letter Sets, Number Series, Letter Series, Word Series tasks and EPS Visuospatial processing: Card Rotation and Hidden Patterns Divergent thinking: Alternate Uses and Opposites task Verbal episodic memory: HVLT immediate, delayed, and free recall | RCT – 3 treatment arms: EG, CG and a wait-list control. Pre-post measures: no follow-up | Training participants showed improvement in Reasoning (Letter Sets, Number Series, Letter Series, and Word Series) relative to the two other groups. Likelihood ratio tests for group differences in latent change in Reasoning verified that Training participants showed more change than both Engagement, $X^2(1) = 23.30$, and Waitlist, $X^2(1) = 15.64$, participants, and that the Engagement and Waitlist groups did not differ from each other, $X^2(1) = .21$. EG showed improvement in Divergent Thinking (Alternate Uses task, Opposites task,). Neither the Waitlist nor the Training group showed significant retest effects on this measure and the change in Divergent Thinking in the EG exceeded that in both the Training, $X^2(1) = 17.61$, and Waitlist, $X^2(1) = 23.78$, groups More cognitively intact participants at baseline showed more gain in both EG and Training group with a stronger relationship found in the Training group than in the EG. |

| Controlled Trials | | | | | | | | | | |
|--------------------------|-------|---|--|---|---|---|----------|--|--|--|
| Carlson et al. (2009) | USA | 17 100% | EC group: 68.0 (5.0) CG: 67.8 (3.7) 60+ | EC group: 12.4 (1.3) CG: 11.6 (2.5) | EC group: 24.5 (3.6) CG: 26.4 (1.7) | EC programme – volunteer senior service in elementary schools. 15 hours per week | 6 months | EF: Flanker test, small circle congruent and incongruent, large circle congruent and incongruent | Controlled trial, not randomised – EC compared to waitlist control Pre-post measures: no follow-up | EC group showed a significant reduction in interference scores compared to CG ($p < .05$). EC group showed significant improvement in accuracy in the incongruent condition only ($p < .05$). |
| Dannhauser et al. (2014) | UK | 67 (42%) | 73.9 (8.3) | NR | 26.3 (2.6) All participants had a diagnosis of MCI | ThinkingFit programme consisting of three activities: physical activity- a minimum of three, 30-45 min sessions per week at moderate heart rate intensity, group-based cognitive stimulation training - weekly 2.5 hr sessions, individual cognitive stimulation training (ICST) -3 times per week for a minimum of 30 minutes. | 12 weeks | Memory: digit span forwards and backwards. Verbal fluency: Letter fluency Category fluency Psychomotor Speed: TMT A, EF: TMT B | Open label study with participants serving as their own controls. Pre-post measure data collected at T0, T1 and T2 : no follow-up | Significant improvement in backwards digit span ($p < .001$), with T2 showing significant improvement over both T0 and T1. |
| Kamegaya et al. (2012) | Japan | 42 n = 30 (included) 86.7% n =12 (not included) 83.3% | n = 30 (included) 73.7 (5.5) n =12 (not included) 75.0 (7.7) 65 – 86 | n = 30 (included) 11.6 (3.8) n =12 (not included) 11.4 (2.9) | n = 30 (included) 28.4 (1.5) n =12 (not included) 27.3 (2.0) | 12-week control period - participants received an educational lecture on nutrition during the control period. Intervention programme comprised of weekly sessions of pleasant physical activity, leisure activities and educational lectures. Senior citizen volunteers were trained to facilitate and maintain a pleasant and comfortable atmosphere, empathetic communication, praise, having a social role; and errorless learning. | 12 weeks | 5-Cog test consisting of character position referencing (attention), cued recall (memory), clock drawing (visuospatial functioning), category fluency (verbal fluency), analogy (abstract reasoning) EF: WDSST , TMT | Open label study with participants serving as their own controls. Pre-post measure data collected at T0, T1 and T2 : no follow-up | In the intervention period, significant improvement was seen on the on WDSST ($p < .05$). Significant improvement was also found on “Cued recall task” of the Five-cog test ($p < .001$), however, a significant effect was also found at baseline therefore repeated learning could not be ruled out. Results for participants with aMCI did not differ from those without aMCI. |

| | | | | | | | | | | |
|----------------------|-------|--|---|--|--|---|---------|--|--|---|
| Li et al. (2014) | China | 45 IG: 45% CG: 35% | IG: 68.6 (5.7) CG: 71.7 (4.0) 60+ | IG: 13.3 (3.1) CG: 14.7 (3.3) | NR MoCA: IG: 26.3 (2.7) CG: 25.2 (2.5) | IG: multimodal intervention comprising cognitive training (three 1 hour sessions per week), Tai Chi (three 1 hour sessions per week) and group counselling (one 90 minute session per week) which included life history review with a focus on career, family and health and the encouragement of interpersonal communication and friendship development. CG: attended two 120 minute lectures on health and ageing. | 6 weeks | Memory: PALT, digit span forwards and backwards Verbal fluency: Category fluency SA/Inhibition: Stroop Test EF: TMT | Controlled trial, not randomised – IG compared to CG Pre-post measures: no follow up | Significant improvement on PALT occurred in the IG ($p < .05$) but not the CG. Performance on the TMT was unchanged in the IG but declined significantly in the CG ($p < .05$). |
| Noice et al; (2004) | USA | 124 Theatre: 79.5% Visual Arts: 77.8% CG: 77.1% | 73.7 (5.99) 60 - 86 | NR Attended college: Theatre: 68.2% Visual Arts: 72.0 CG: 70.6 | NR Screened using SPMSQ to exclude those without intact cognitive functioning | Theatrical training – seven 90 minute sessions of instruction in professional acting techniques, which did not involve intentional memorising of scripts. Visual Arts - seven 90 minute sessions of instruction in a wide variety of visual art forms. CG- no treatment | 4 weeks | Memory: Word recall Working memory: Listening span Problem-solving: MEPSP | Controlled trial, not randomised – Theatre group, Visual Arts group and CG compared Pre-post measures: follow-up at 4 weeks post-test and at 4 months post-test for Theatre group | Theatre group performed better than the CG on all three dependent measures, with significant improvement on word recall ($p < .01$) and problem-solving ($p < .05$). The theatre group also scored higher than the visual arts group on problem solving ($p < .001$). In the Theatre group at 4-month follow-up problem-solving and memory span performance did not decline and recall performance increased ($p = .012$). |
| Noice & Noice (2006) | USA | 21 72.2% (completers) | 82.33 (5.64) 72 - 95 | NR | NR Screened using SPMSQ to exclude those without intact cognitive functioning | Theatrical training - twice-weekly one-hour sessions of instruction in professional acting techniques, which did not involve intentional memorising of scripts. | 4 weeks | Memory: Word recall Working memory: Listening span Problem-solving: MEPSP | Open label study with participants serving as their own controls. Pre-post measure data collected at T0, T1 and T2 : no follow-up | Improvements were found on all three measures post-intervention with significant improvements on word recall ($p < .05$) and problem-solving ($p < .05$). |

| Non-Controlled Trial | | | | | | | | | | |
|-----------------------------|-------------|--------------|-----------------|----|----|---|---------|---|---|--|
| Noice et al. (1999) | Switzerland | 13 NR | NR 65-82 | NR | NR | <p>Theatrical training - 11 sessions of instruction in professional acting techniques, which did not involve intentional memorising of scripts.</p> <p>Strong strategy: participants received scripts with handwritten marginal notations making explicit the goals and motivations of the characters.</p> <p>Weak strategy: character goals and motivations implied by the printed dialogue.</p> | 4 weeks | Memory: Immediate and delayed list recall, immediate and delayed recognition, cued recall, accessibility measure* | Random allocation to two conditions, no CG Pre-post measures: no follow-up | <p>Overall, participants showed significant improvement on free and delayed recall ($p < .05$) and immediate and delayed recognition scores ($p < .05$) after the intervention.</p> <p>Participants receiving the strong version of the acting strategy demonstrated significantly faster access to stored material, as measured by the accessibility of text measure than those receiving the weak version ($p < .05$).</p> |

Note. SD = Standard Deviation; MMSE = Mini Mental State Examination; EC = Experience Corps; CG = Control Group; CFT = Complex Figure Test; EF = executive function; TMT = Trail Making Test; RCT = Randomised Controlled Trial; PC = Participation-centred; ACTIVE = Advanced Cognitive Training for Independent and Vital Elderly; GCS = Global Cognitive Score; T = Time; NR = Not reported; IG = Intervention Group; CEARD = Consortium to Establish a Registry for Alzheimer's Disease; SA = Selective attention; Wechsler Digit-Symbol Substitution Test = WDSST; Yamaguchi Kanji-Symbol Substitution Test = YKSST; RBANS = Repeatable Battery of Neuropsychological Status; AKT = Non-Verbal Geriatric Concentration Test; FAIR = Frankfurt Attention Inventory; NVLT Non-Verbal Learning Test; MDRS = Mattis Dementia Rating Scale; Chinese Auditory Verbal Learning Test = CAVLT; BCT = Bell Cancellation Test; WAIS-R = The Wechsler Adult Intelligence Scale-Revised; BNT = Boston Naming Test; SPMSQ = Short Portable Mental Status Questionnaire; EBMT = East Boston Memory Test; MEPS = Means End Problem Solving Procedure; EXPT = Experiment; EG = Engagement Group; MoCA = Montreal Cognitive Assessment; EPS = Everyday Problem-Solving; HVLT = Hopkins Verbal Learning Test; MCI = Mild cognitive impairment; PALT = Paired Associative Learning Test; *measures not validated

Quality appraisal

Each study was reviewed by the first author using the Downs and Black (1998) checklist. A second rater, a trainee clinical psychologist, independently reviewed five papers, which were selected to represent different levels of quality, to assess the reliability of ratings. There was exact agreement on 83% of ratings (116 out of 140) with Cohen's kappa (κ) indicating a substantial level of agreement between the raters ($\kappa = 0.66$; Landis & Koch, 1977). Differences between ratings were discussed by the reviewers and consensus ratings agreed. Table 2. presents the quality rating scores for the review studies with eleven studies receiving a "*moderate*" rating and six a "*low*" rating, with none achieving a "*good*" or "*excellent*" rating.

The overall strengths of the studies included clearly stated aims or hypotheses, main outcomes were clearly described as were the patient characteristics, the interventions, and the main findings. Participants were recruited from the same populations and appropriate measures were used. The key methodological limitations included a lack of reporting on adverse events and compliance with the intervention, sample representativeness, not blinding participants to the intervention received, the researcher measuring the outcomes and lack of concealment of the randomised intervention assignment. None of the studies reported a sample size or power calculation and there was not enough information to determine whether the statistical tests used were appropriate. Where statistically significant results were found only one study reported effect sizes (Stine-Morrow et al., 2014). Where sufficient information was available, effects sizes were calculated in order to interpret the results in a more meaningful way.

Table 2 Quality ratings of studies

| Quality criteria | Carlson et al (2008) | Carlson et al (2009) | Cohen-Mansefield et al (2015) | Dannnhauser et al (2014) | Dodge et al (20015) | Kamegaya et al (2012) | Kamegaya et al (2014) | Kattenstroth et al (2013) | Li et al (2014) | Maki et al (2012) | Mortimer et al (2012) | Noice et al (1999) | Noice et al (2004) | Noice & Noice (2006) | Noice & Noice (2009) | Noice & Noice (2013) | Stine -Morrow et al (2014) |
|--|----------------------|----------------------|-------------------------------|--------------------------|---------------------|-----------------------|-----------------------|---------------------------|-----------------|-------------------|-----------------------|--------------------|--------------------|----------------------|----------------------|----------------------|----------------------------|
| 1.Aims & hypothesis | 1 | 0 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 |
| 2.Outcomes | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| 3.Patient characteristics | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 0 | 0 | 1 | 1 | 1 | 1 |
| 4.Interventions described | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| 5.Confounders | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 0 | 1 | 0 | 1 | 1 | 2 |
| 6.Main findings | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 |
| 7.Variability | 0 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 |
| 8.Adverse events | 0 | 1 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 9.Characteristics of attrition | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 1 | 1 |
| 10.Probability values | 0 | 0 | 0 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 0 | 0 | 0 | 0 |
| 11.Representative sample - invited | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 |
| 12. Representative sample - participated | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 13.Representative facilities and staff | 1 | 0 | 0 | 0 | 0 | 1 | 1 | 1 | 0 | 1 | 1 | 0 | 1 | 0 | 1 | 1 | 1 |
| 14.Subject blinding | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| 15.Researcher blinding | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 16. Data-dredging | 1 | 1 | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 |
| 17.Follow-up | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |

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|-------------------------------|----------|-----|----------|----------|----------|----------|----------|-----|-----|----------|----------|-----|----------|-----|----------|-----|----------|
| 18.Statistical tests | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 19.Compliance | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 1 |
| 20.Outcome measures | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 |
| 21.Recruitment population | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 0 |
| 22.Recruitment time period | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 0 |
| 23.Randomised | 1 | 0 | 1 | 0 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 0 | 0 | 1 | 0 | 1 |
| 24.Concealment | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 25.Adjustment for confounders | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| 26.Attrition accounted for | 0 | 0 | 0 | 1 | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 |
| 27.Sufficient power | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Total (maximum 28) | 15 | 10 | 16 | 16 | 19 | 16 | 14 | 12 | 12 | 19 | 17 | 9 | 15 | 10 | 14 | 12 | 15 |
| Percent | 54% | 36% | 57% | 57% | 68% | 57% | 50% | 43% | 43% | 68% | 61% | 32% | 54% | 36% | 50% | 43% | 54% |
| Quality rating | moderate | low | moderate | moderate | moderate | moderate | moderate | low | low | moderate | moderate | low | moderate | low | moderate | low | moderate |

Note: Quality ratings: 1 = yes, 0 = no, 0 = unable to determine (Question 5. 2 = yes, 1 = partially, 0 = no) See Appendix 2. for quality rating criteria details.

Randomised controlled trials

The search identified 10 RCTs. The trials conducted by Dodge and colleagues (2015) and Maki and colleagues (2012) were methodologically the strongest (both assessed as of 'moderate' methodological quality; 68%). Dodge and colleagues' (2015) six-week trial compared an internet-facilitated face-to-face daily communication intervention with a control group in both cognitively intact participants and those with MCI. Although memory (immediate, delayed and working), verbal fluency, psychomotor speed, executive functions, selective attention, and inhibition were all measured, significant improvement was found only in verbal fluency and this improvement was limited to cognitively intact participants (measured by the Clinical Dementia Rating scale, CRD). The significant increase was found in semantic fluency at post-trial with a large effect (not maintained at follow-up). A significant improvement was reported in phonemic fluency at follow-up but it was not possible to determine the effect size. This study achieved high adherence rates and no drop-outs with participants whose average age was 80 years. This intervention focussed solely on increasing social interaction. In the trial conducted by Maki and colleagues (2012), the three-month intervention aimed to facilitate daily walking habits in small groups. Participants also planned and executed walking excursions and so the combined benefits of exercise and social interaction were expected. The control group received educational lectures unrelated to cognitive decline. While attention, memory (cued-recall), visuospatial functioning, verbal fluency, abstract reasoning, sustained attention, psychomotor speed and executive functioning were measured a significant improvement was found only in verbal fluency (semantic fluency) with a small effect.

Mortimer and colleagues (2012), rated 'moderate'; 61%, compared Tai Chi, walking, social interaction (discussion group) and a no-intervention control, over the course of 40 weeks.

Global cognition, memory, verbal fluency, visual neglect, visuospatial functioning, executive functioning, psychomotor speed, selective attention and inhibition were measured. When compared to the control group, the Tai Chi group showed significant improvements, with moderate effects, in global functioning and on the initiation, attention and memory subscales of the Mattis Dementia Rating Scale, as well as psychomotor speed (Trail Making Test-A, TMT-A, only) and with small effects in executive functioning (TMT-B, only) and memory (Chinese Auditory Verbal Learning Test, CAVLT, delayed recognition only). The social interaction group showed significant improvement on verbal fluency (semantic fluency only) with a moderate effect, which was comparable to the effect in verbal fluency found in the Tai Chi group. No difference was found between the walking and control group.

Cohen-Mansfield and colleagues (2014), rated 'moderate'; 57%, compared three different 10 week long interventions for older people with self-reported memory difficulties; health promotion, cognitive training and a participation-centred course, with a wait-list control. The participation-centred course involved the delivery of memory, cognitive, organisational, and social interaction strategies in a book-club context described as meaningful as having the potential to increase knowledge and promote social interaction (Luyt, Chow, Ng, & Lim, 2011). Global functioning was measured, with all three interventions resulting in significant improvement with small effects. This was a small pilot study and the lack of a differential effect could be a result of limited power.

In the study conducted by Kamagaya and colleagues (2014), rated 'moderate'; 50%, the intervention group participated in a weekly two-hour programme of physical and leisure activities for 12 weeks. Healthcare professionals conducting the activities were supported by volunteers whose role was to support participants who required assistance in engaging in the programme, facilitate interactive communication, and to maintain a 'pleasant

atmosphere'. The control group received no intervention. Whilst attention, memory, visuospatial functioning, verbal fluency, reasoning and executive function were measured, the intervention group showed a significant improvement only in abstract reasoning compared to controls with a small effect.

Carlson and colleagues (2008) study, rated 'moderate'; 54%, compared Experience Corps®, a high-intensity volunteer senior service in elementary school settings in which participants were trained to support children with reading, classroom behaviour and library use, and a wait-list control. Duration of participation was for 15 hours per week for between 4 to 8 months, with results adjusted for length of exposure. Memory (immediate and delayed), executive function, visuospatial functioning and psychomotor speed were measured. Overall there were no significant differences between the intervention and control group. However, those in the intervention group with impaired baseline executive function showed improvement in executive function (42%) and memory (40%, delayed recall) compared to impaired controls who showed declines. The differences were described as statistically and clinically significant, however, there was insufficient data reported to calculate effect sizes. High retention and adherence were achieved with participants who were predominantly African American, with low income and formal education, with this study including participants with one of the lowest reported MMSE scores.

Stine-Morrow and colleagues (2014), rated 'moderate'; 54%, compared the *Senior Odyssey Project*, an engagement intervention involving a team-based competitive programme in creative problem solving, with a home-based cognitive training intervention and a wait-list control group. Processing speed, reasoning, visuospatial processing, divergent thinking and memory (verbal episodic) were measured. The authors predicted selective cognitive improvement in the cognitive training group and generalised improvement in the socially

complex programme of creative problem solving, however, they found both groups showed ability-specific effects. The cognitive training group showed significant improvement only in reasoning compared to the engagement and control group and the engagement group significantly improved only in divergent thinking compared to the cognitive training and control group both with small effects. Differential effects were reported across ages for improvement in divergent thinking in the engagement group as .7 in younger older adults (63.4 years) and less than .2 in the older old (79.7 years). Furthermore, cognitively intact participants at baseline in both groups showed more gain. Participants in this study had the greatest amount of education and adherence and retention was high in both intervention groups.

A series of studies researched a theatrical intervention (Noice & Noice, 2006, 2009, 2013; Noice et al., 1999; Noice et al., 2004). The acting intervention involved training in professional acting skills (which did not involve the deliberate memorisation of scripts) twice-weekly over the course of four weeks and culminated in full performances of scenes from memory. Noice and Noice (2009), rated 'moderate'; 50%, compared acting, singing and wait-list controls in participants who were on average over the age of 80 years and living in subsidised, mainly low-income, retirement homes. Memory (immediate and delayed), verbal fluency (semantic fluency) and problem-solving were measured. Significant increases were found for the acting group in memory (immediate and delayed; but not on East Boston Memory Test, EMBT immediate or digit span), verbal fluency and problem-solving compared to the singing and control group. With large effects in improvements in memory (immediate and delayed; EMBT) and problem-solving and moderate effects in memory (delayed; word list) and verbal fluency. In their later study (Noice & Noice, 2013), rated 'low'; 43%, the same acting intervention was investigated and the same measures administered. In their previous

study, the intervention was delivered by the expert who devised it. In this study, the intervention was either delivered by retirement home activity directors, with no previous theatrical experience, or an outside professional acting teacher who received minimal training in delivering the intervention. The participants were retirement home residents, with an average age of over 80 years. In the condition where the intervention was delivered by the activity director, a significant increase was found in problem-solving, with large effect, when compared to controls and where the intervention was delivered by an outside acting teacher significant improvement was found in memory (immediate recall; word list only) and problem-solving, both with large effect, and in verbal fluency with moderate effect.

Kattenstroth and colleagues (2013), rated 'low'; 43%, investigated a six-month long dance intervention, where participants met weekly for an hour and a half, which was compared to a no-intervention control group. The overall cognitive performance was measured along with selective attention and concentration, and non-verbal learning. Significant improvements were found in overall cognitive performance, selective attention and concentration (signs) and non-verbal learning, with large effects, and selective attention and concentration (errors) with small effect. Notably, there were no changes in cardio-respiratory fitness.

Controlled trial

There were six controlled trials identified through the search process. Dannhauser and colleagues (2014), rated 'moderate'; 57%, compared a 12-week ThinkingFit complex multimodal activity intervention with participants, all of whom had a diagnosis of MCI, serving as their own controls. The intervention, consisting of five and a half hours per week, incorporated physical activity, group-based stimulation training and individual cognitive

stimulation training. Memory, verbal fluency, executive function and psychomotor speed were measured. Compared to the control period, significant improvement was found only in memory (backwards digit span) with small effect. High recruitment and adherence rates with participants with low levels of pre-existing physical activity were reported. Kamegaya and colleagues (2012), also rated 'moderate'; 57%, compared a 'pleasant' physical exercise programme, similar to that described in the later study (Kamegaya et al., 2014) where participants served as their own controls. Attention, memory, visuospatial functioning, verbal fluency, reasoning and executive function were measured. Compared to the control period significant improvement was found in executive function (Wechsler Digit-Symbol Substitution Test, WDSST), with small effect, and in memory (cued recall task), with moderate effect. However, a significant effect was found at baseline in the cued recall task and therefore practice effects cannot be ruled out. There was no difference between those with and without MCI.

Noice and colleagues (2004) and Noice and Noice (2006) conducted controlled trials of the theatrical intervention previously described. Noice and Noice and colleagues (2004), rated 'moderate'; 54%, non-randomly assigned participants to either an acting, visual arts, or a control group. Memory and problem solving were measured. The acting group performed significantly better than the control group on both memory (word list, moderate effect; listening span, small effect) and problem-solving (with small effect). The visual arts group improved significantly on memory (word list) with small effect. At 4-month follow-up participants in the acting group showed no decline in memory (listening span) or problem-solving and memory performance (word list) significantly improved with small effect. Noice and Noice (2006), rated 'low'; 36%, studied 21 residents in a long-term care facilities who were on average aged over 82 years with relatively high socioeconomic status, serving as

their own controls. Memory and problem solving were measured with significant improvements found in memory (word recall) with small effect and problem-solving with large effect. However, there was also a significant improvement in problem-solving during the control period thus raising the possibility of practice effects.

Studies by Carlson and colleagues (2009) and Li and colleagues (2014) both employed functional magnetic resonance imaging (fMRI) to assess the functional brain activity (not reviewed here), as well as administering cognitive measures. Sample sizes were relatively small (eight and 45 respectively). Li and colleagues (2014), rated 'poor'; 43%, compared a multimodal intervention comprising cognitive training, Tai Chi and group counselling, totalling seven and a half hours per week over the course of six weeks, with a control group who attended two 120 minute lectures on health and ageing. Memory, selective attention, inhibition, and executive function were measured. When compared to the control group, only memory significantly improved (Paired Associative Learning Test, PALT, only). Executive function significantly declined in the control group compared to the intervention group. It was not possible to determine the effect sizes and it is, therefore, difficult to comment on how meaningful these results are. Carlson and colleagues (2009), rated 'low'; 36%, compared participants allocated to the previously described Experience Corps® intervention for six months to a wait-list control. Executive function was measured with significant improvement found in the intervention group when compared to the control group (improvement in interference scores on flanker task and accuracy in the incongruent condition only). Again, it was not possible to determine the effect sizes.

Non-controlled trial

One non-controlled trial was identified through the search process. Noice and colleagues (1999), rated 'low'; 32%, studied a theatrical intervention (previously described) involving 13 participants. The main interest was in the overall effectiveness of the intervention, with a secondary consideration concerned with the comparison of the effectiveness of 'weak' and 'strong' versions of the actors' strategy employed during the first half of the 4-week study. Memory was measured with participants showing significant improvement (immediate and delayed recall and recognition) however it was not possible to determine the effect sizes. Participants in the 'strong' version of the intervention showed significantly faster access to stored script material than those in the weak version, however, this result was based on data collected using an outcome measure which has not been validated. This study received the lowest quality rating.

In summary, studies which achieved a 'moderate' rating for methodological quality, and where effect sizes were available, reported significant improvements in verbal fluency, specifically semantic fluency, with large (Dodge et al., 2015), moderate (Mortimer et al., 2012; Noice & Noice, 2009) and small effect (Maki et al., 2012). Significant improvements in memory were also of large (Noice & Noice, 2009), moderate (Noice & Noice, 2009) and small effect (Dannhauser et al., 2014; Noice et al., 2004). Improvements in problem solving were of moderate (Noice & Noice, 2009) and small effect (Noice et al., 2004). With small effects reported for improvements in global cognitive function (Cohen-Mansfield et al., 2014), abstract reasoning (Kamegaya et al., 2014), divergent thinking (Stine-Morrow et al., 2014) and executive function (Kamegaya et al., 2012). It is important to note the proportion of significant results found was relatively low in comparison to the number of outcome measures, assessing different cognitive domains, which were administered.

Discussion

The evidence to date indicates social interaction may protect against cognitive decline and dementia (Kuiper et al., 2015). This review was conducted to systematically evaluate the current empirical evidence for improvement in cognitive function in older adults as a consequence of interventions which increase social interaction. 17 studies were identified for inclusion in the review, all of which reported significant improvement in one or more aspect of cognitive function, however, effect sizes were variable, ranging from small to large, and not sufficiently robust. The studies were generally disparate in terms of methodological quality, design, participant characteristics and cognitive assessment measures, with variation not only in the type of interventions but also their intensity and duration. This made it difficult to compare outcomes across studies and meta-synthesis of the results impracticable.

Overall, the studies were mostly moderate in quality with around a third, low in quality. Only 10 RCTs, which are considered the “gold standard” to investigate causal relationships, were included. This is an emerging area of research and the quantity and quality of studies included were relatively low, with a considerable number based on small samples. No studies reported on power and for some, it was not possible to determine effect sizes making it difficult to assess the validity of results. Although significant improvements, with moderate to large effects, were found in verbal fluency (semantic fluency), memory and problem solving it is important to note the proportion of significant results found was relatively low in comparison to the number of outcome measures, assessing different cognitive domains, which were administered and these findings need to be interpreted with caution. Significant improvement was found in global cognitive function, abstract reasoning, divergent thinking

and executive function but these findings were isolated to individual studies and were small in effect.

The studies were conducted in culturally diverse settings and their findings could be specific to those. All of the studies included may be subject to selection bias as those who volunteered to participate may differ from the general population, they may be healthier and more likely to adhere. It is possible individuals with dementia prodromal cognitive and depressive symptoms might be less likely to volunteer. In addition, there was a notable gender bias in most of the studies, with a greater proportion of females participating, and as such generalisability may be limited. It is possible the impact of increased social interaction differentially affects men and women. Zunzunegui, Alvarado, Del Ser, and Otero (2003) found engagement with friends was protective for cognitive decline in women but not men. Furthermore, only two of the studies included post-test follow-up, with the longest being 12 weeks. In order to confirm whether the rates of decline in cognitive functions are different between the intervention and control groups, participants would need to be monitored for at least six months to one-year post-intervention in order to compare the natural history of cognitive decline (Dodge et al., 2015).

In terms of the interventions, the majority could be considered multi-modal where the combined effects of increased social interaction and other factors, such as increased physical or cognitive activity, were expected and therefore where improvements were reported the contribution of increased social interaction was indeterminable. This raises the question is it the “doing” or the “doing with” that is important. In a recent study, Litwin and Stoeckel (2015) found being engaged in a large variety of activities was primarily of benefit to those with limited, or no social ties, and suggest it is the social component of participating in activities which is beneficial in later life. Two of the most methodologically robust studies

included in this review (Dodge et al., 2015; Mortimer et al., 2012) did include interventions which focussed solely on increasing social interaction. In both cases, a significant improvement (with large and moderate effect) was found in semantic fluency. Individuals with Alzheimer's disease exhibit impairment in both phonemic and semantic fluency, with more prominent deficits in semantic fluency (Butters, Granholm, Salmon, Grant, & Wolfe, 1987; Haugrud, Crossley, & Vrbancic, 2011; Henry, Crawford, & Phillips, 2004; Monsch et al., 1992; Rascovsky, Salmon, Hansen, Thal, & Galasko, 2007). In addition, semantic fluency has been found to decline at a faster rate in individuals with Alzheimer's disease (Clark et al., 2009). However, in the study conducted by Mortimer and colleagues (2012), cognitive improvement in the Tai Chi group was found in other domains and was not restricted to semantic fluency as in the social interaction condition. Notably, the improvement in semantic fluency with large effect found by Dodge and colleagues (2015) was achieved as a consequence of a 6-week intervention whereas the moderate effect found by Mortimer and colleagues (2012) was after a 40-week intervention, suggesting it may be more costly and less efficacious.

The precise mechanism through which social interaction may impact cognition is unclear although a number of hypotheses have been proposed. These include the "disuse" perspective on cognitive ageing (Salthouse, 1991) which suggests that changes in patterns of activities result in disuse and consequently atrophy of cognitive skills and processes – the so-called "use it or lose it theory" (Hultsch, Hertzog, Small, & Dixon, 1999). The related theory of cognitive reserve explains how various life-exposures, such as level of education, seem to be associated with resilience against age- or pathology-related impairment of cognitive function and explains how some individuals can endure more of these changes whilst maintaining function (Stern, 2002; Stern, 2012). This concept comprises brain reserve, which

refers to structural differences in the brain that may increase tolerance to pathology, and cognitive reserve whereby individual differences in cognitive processes or neural networks make them more efficient, adaptive, or plastic, allowing some people to cope better than others with cognitive decline (Kramer, Bherer, Colcombe, Dong, & Greenough, 2004; Stern, 2009). The Scaffolding Theory of Ageing and Cognition (STAC and STAC-r, Goh & Park, 2009; Reuter-Lorenz & Park, 2014) shares some similarities with the cognitive reserve theory (Ballesteros, Kraft, Santana, & Tziraki, 2015). STAC proposes ageing is associated with declines in both neural structures (“neural challenges”) and neural function and that the brain responds to this by reorganising or creating neural scaffolds, comprising compensatory frontal recruitment, more distributed neural processing, and neurogenesis, which serve as supportive structures preserving cognitive function. In addition, STAC proposes scaffolding can be enhanced by external experiences including social engagement (Schaie & Willis, 2015). Stress-adaptation failure has also been implicated in the development of Alzheimer’s disease (Deshmukh & Deshmukh, 1990) and it is proposed social interaction acts as a protective buffer against stress (Kuiper et al., 2015).

Strengths and limitations of the review

This is the first known systematic review of the current research evidence base to investigate whether interventions which aim to increase social interaction in older adults can improve their cognition. The search was systematic and comprehensive. Although it used strategies similar to those employed in other systematic reviews, it is possible relevant studies may have been missed or overlooked. In order to minimise these issues, authors of included papers were contacted in an attempt to identify further relevant studies and unpublished work, which did result in the inclusion of additional studies. In addition, the exclusion of theses and non-English language sources may have resulted in relevant studies not being

included. Furthermore, it is possible the exclusion of unpublished studies could have introduced bias to the review. There is evidence authors are more likely to submit statistically significant results for publication and statistically significant findings are more likely to be published than negative findings. Moreover, there is evidence of selective reporting of outcomes in publications whereby results which are not statistically significant are inadequately reported or omitted completely. Thus publication processes may introduce a systematic bias which has a tendency to inflate intervention effects (Petticrew & Roberts, 2006).

This review aimed to provide an inclusive synthesis of the limited literature in this emerging research area and consequently studies of varying quality were included. Although this allows for a wider understanding of current evidence to be presented, the high degree of heterogeneity within the studies resulted in challenges synthesising the data. It was not feasible to conduct a meta-synthesis of the results, instead, a narrative synthesis was employed. In terms of the quality assessment, although substantial inter-rater agreement was achieved this was based on the ratings of around 30% of the studies as only five of the 17 articles were second rated.

Some limitations in relation to the Downs and Black checklist should be noted. The authors have assigned equal weighting to each of the five subscales. They explained this is based on a lack of evidence to prioritise one subscale over the other rather than to suggest each subscale is of the same importance (Downs & Black, 1998). However, the assumption subscales are of equal weighting may result in total scale scores which do not accurately reflect the methodological quality of the studies rated and thus care should be taken in their interpretation. In addition, the checklist has been criticised for the large number of questions relating to reporting which are not directly related to quality or potential bias (Deeks *et al.*,

2003). The inclusion of which may be misleading as a study containing methodological bias but which is well reported can potentially be rated as of higher quality.

The majority of the studies included employed multi-modal interventions and it was not possible to determine what contribution, if any, was made by increasing social interaction. In the studies in which interventions focussed exclusively on increasing social interaction neither explored the mechanisms of increased social interaction on cognitive function.

Implications for practice and future research

This review highlights the need for more specific and methodologically robust research to understand the contribution, mechanisms, and potential benefits of social interaction on cognitive function in older adults. Well-designed, sufficiently powered, randomised controlled studies with large homogenous samples of participants who are representative of the population, and include adequate follow-up period, and use a universal battery of validated cognitive outcome measures are warranted. Future studies should aim to determine the mechanisms of change and the specific contributions of social interaction in multi-modal interventions. Interventions which consist exclusively of social interaction need to be compared to other types of interventions aimed at increasing cognitive function in older adults in order to develop the most effective protocols, which are cost-effective, and can easily be integrated with community settings. This review found a greater proportion of significant improvements were in semantic fluency and memory, both of which are domains frequently impaired in people diagnosed with Alzheimer's disease. Further research would be useful to clarify if these areas are more amenable to change and whether targeted interventions might be beneficial and also to determine the clinical significance of improvements.

Differential findings within some studies found that those who were cognitively intact were more likely to improve than those who were cognitively impaired, or had a diagnosis of MCI (Dodge *et al.*, 2015; Stine-Morrow *et al.*, 2014). Similarly, those who were younger were shown to improve more than older participants (Stine-Morrow *et al.*, 2014). This highlights the importance of conducting research with homogenous samples and comparing the impact of interventions across different groups. It is possible people with differing levels of cognition would benefit from differing types of social intervention or a more structured/facilitated approach. Likewise, some interventions may be beneficial for younger older adults but perhaps less so for older older adults. Understanding these potential nuances is important in the development and delivery of cost-effective interventions.

From a public health perspective, although the evidence around interventions which increase social interaction is not definitive and therefore insufficient to guide public health policy at this time, there is an established link between social interaction and cognitive function in epidemiological studies and health practitioners, community groups, and policymakers should consider the potential benefits of enhancing social interaction in older adults.

Conclusion

This review found the existing research on interventions, which aim to increase social interaction, in older adults to be very limited in terms of quantity, methodological quality, and homogeneity of participants and as such no definitive conclusions can be drawn. This is, however, an encouraging area of research with all of the studies included in this review reporting some significant cognitive improvement after short-term interventions, albeit with varying effects, in a population characterised by age-related cognitive decline. The contribution of social interaction to these results remains largely indeterminable because of

the multimodal nature of most of the interventions. However, there was some tentative support for improvement in semantic fluency in the limited studies which focussed solely on increasing social interaction. This is of particular interest because of the associated deficits and accelerated decline in this domain evident in Alzheimer's disease. As the population ages, the number of people experiencing dementia is expected to rise sharply. In addition, there is evidence to suggest the quantity and/or the quality of social relationships in industrialised societies is decreasing (Holt-Lunstad et al., 2010). Further research is important in order to understand the role of social interaction in cognitive decline and dementia and to determine whether interventions which seek to increase it can improve their cognitive outcomes.

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The Authors declare that there is no conflict of interest.

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‘This is my life and I’m going to live it’: A grounded theory approach to conceptualising resilience in people with mild to moderate dementia

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Journal article abstract

Background: Interest in resilience has increased over recent years because of its potential impact on health, well-being, and quality of life. To date, little research into resilience has involved people with a diagnosis of dementia.

Objectives: To develop a grounded theory of the concept of resilience in people with dementia.

Methods: Seven semi-structured interviews were conducted with people with dementia; a social constructivist version of grounded theory informed the collection and analysis of data.

Results: The model hypothesises resilience is a process of '*overcoming dementia*'. For participants this meant maintaining a sense of pre- and post-diagnostic continuity which was achieved through a complex interaction of their approach to life and acceptance of dementia in conjunction with spousal and other social support.

Conclusions: Resilience is conceptualised as comprising individual, social, community, societal and cultural aspects, opening up the possibility of promoting resilience through the development of psychosocial interventions.

Keywords; dementia, resilience, grounded theory, coping, adjustment

Word count: 147

Introduction

The rapid expansion in resilience research over recent years reflects the increasing interest of practitioners and policymakers in its potential impact on health, well-being, and quality of life (Windle, Bennett, & Noyes, 2011).

The origins of resilience research can be traced back to child and adolescent developmental psychology in the 1960s and 1970s (see Luther, 2006, for review) when children, considered to be at high risk for psychopathology, were identified as having unexpectedly healthy patterns of adaptation (Garmezy, 1974; Rutter, 1979; Werner & Smith, 1982). A shift from the identification of risk factors for psychological problems to the identification of individual strengths ensued with a focus on identifying protective factors, or assets, which enabled young people to positively negotiate adversity and 'bounce back' (Dyer & McGuinness, 1996; Luthar & Cicchetti, 2000; Luthar, Cicchetti, & Becker, 2000; Masten, 2001; Masten et al., 1999). Subsequently, resilience research has focussed on the *process* of positive adaptation despite experiences of significant adversity, rather than individual characteristics (Luthar, 2006).

Although the majority of resilience research has been conducted within the field of childhood development (Windle, 2012), the concept has been increasingly applied to other disciplines and populations (Sarre et al., 2013), including older people (Hildon, Montgomery, Blane, Wiggins, & Netuveli, 2009; Hildon, Smith, Netuveli, & Blane, 2008; Wild, Wiles, & Allen, 2011; Wiles, Wild, Kerse, & Allen, 2012; Windle, Markland, & Woods, 2008).

Within the field of gerontology, the concept of resilience is of growing interest, with researchers arguing that older people can be considered to be ageing well despite living with

significant illness or hardship (Harris & Keady, 2008; Wiles *et al.*, 2012). This challenges traditional definitions of successful ageing which have emphasised the absence of physical and cognitive disabilities (Baltes & Baltes, 1990). For example, Rowe and Kahn (1997, 1998) characterised successful ageing as comprising three components: social and productive engagement, high cognitive and physical functioning and freedom from disease and disability. With a focus on physical functioning and lack of disability, such models may lead to the conclusion that most people are ageing unsuccessfully due to the high prevalence of disease and disability in later life (Phelan, Anderson, Lacroix, & Larson, 2004).

Although the concept of resilience is increasingly being applied to later life there are inconsistencies in how it is defined and used within this population (Wild *et al.*, 2011). Resilience has been defined as exposure to adversity and positive adaptation, whereby positive adaptation is characterised as 'doing okay', rather than flourishing or superior functioning. 'Doing okay' has been assessed as maintained or increased results on measures of quality of life, well-being, or mood after experiencing adversity (Hildon *et al.*, 2009; Netuveli, Wiggins, Montgomery, Hildon, & Blane, 2008; Windle, Woods, & Markland, 2009). Older people with resilient outcomes have been reported to draw on a broader range of social and individual resources, in particular resources which stabilise life changes by providing continuity (Hildon *et al.*, 2008). In a study of older people's understandings and experiences of resilience, Wiles and colleagues (2012) identified resilient characteristics which although could be considered personal or internal, were all deeply embedded in physical and social contexts; they propose resilience is a contextualised process with both individual and environmental aspects. Additionally, based on the synthesis of over 270 research articles, Windle (2011; 2012) proposed an ecological model, whereby assets and resources at the level of the individual, community, and society facilitate the capacity for

resilience in older adults. Furthermore, Wiles and colleagues (2012) argue that different aspects of resilience, such as physical wellbeing, mobility, and social relationships should be considered and that resilience is the outcome of the balancing of strengths and constraints across these areas. Thus even older people experiencing illness or difficulties in some areas can be conceptualised as being resilient and ageing well. Similarly, Harris (2008) argues that unlike successful ageing, resilience is achievable by people regardless of their background or cognitive or physical impairments, including those with dementia.

There are over 44 million people worldwide with dementia, with this figure predicted to increase to over 75 million by 2030 (Prince et al., 2013). Given the prevalence, economic, and social cost of dementia it remains a relatively neglected area of research compared to other major illnesses (Alzheimer's Trust, 2010). One of the greatest challenges in applying a resilience framework to those with dementia is identifying the individual, social and group structures which promote resilience and provide the basis for interventions which foster resilience and living well for the increasing number of people with the condition (Harris & Carroll, 2016). Unique to this population is the progressive cognitive changes associated with dementia which can threaten a person's ability to actively maintain positive relationships, and relatedly, a positive sense of self. A resilience framework developed for this population would enable social networks and communities to best support people with dementia to maintain, or develop, resilience by working with, or enhancing, their remaining strengths (Harris & Carroll, 2016) thus contributing to the maintenance of functioning and improved quality of life (Williamson & Paslawski, 2015).

Resilience researchers have been criticised as tending to define resilience without reference to those who are at the heart of their studies (Massey, Cameron, Ouellette, & Fine, 2010). Whilst Canvin, Marttila, Burstrom and Whitehead (2009) highlight the potential for a

resilience-based approach to shift the focus from the identification of risk factors for negative outcomes to explaining positive and unexpected outcomes, they emphasise the importance of understanding what people from marginalised populations consider achievements despite the challenges they face, drawing particular attention to the importance of recognising their perspectives and the hugely complex and difficult context in which they live. A limited amount of research on resilience has been conducted with caregivers of people with dementia (Dias et al., 2015; Donnellan, Bennett, & Soulsby, 2016; Harmell, Chattillion, Roepke, & Mausbach, 2011) but little has been conducted with people with dementia themselves. Harris (2008) conducted two case studies, with her findings suggesting it is possible for people with dementia to demonstrate resilience, live with their diagnosis, and continue to live meaningful lives. In addition, Williamson & Paslawski, (2016) conducted interviews with people living with dementia and their caregivers to examine their perspective on the concept of resilience and factors associated with it. They identified eight factors associated with resilience organised under the themes 'active and purposeful living', 'perspective' and 'resources'.

Aims

This study aimed to develop a grounded theory of the concept of resilience in people living with a diagnosis of dementia. It is hoped the theory will illuminate the experience of resilience, how it is developed and maintained, ultimately informing clinical practice and improving support for people with dementia. In addition, resilience provides an opportunity to demonstrate positive outcomes despite dementia and has the potential to challenge stereotypes and stigma associated with this condition (Harris, 2008).

Methods

Design

Grounded theory is a systematic, flexible, methodology for the collection and analysis of qualitative data from which a theory is constructed (Charmaz, 2014). This approach was adopted as it goes beyond description and aims to explain underlying processes. Its use is appropriate when there is a lack of existing theories regarding a process of interest, or when there are theories but not within in a particular population. This study employed Charmaz's (2014) social constructivist version of grounded theory which acknowledges the researcher's role in both the data and analysis, with the theory being constructed through the interaction between the participant and researcher and their current and previous social contexts. In addition to personal experiences, relevant factors which are likely to have influenced the first author include her role as a trainee clinical psychologist and prior experience of working with older adults.

Participants

Purposive sampling was employed (see Appendix 4 for inclusion/exclusion criteria). People were considered eligible to participate in the study if they had a diagnosis of dementia which they had been informed of and were able to retain. In addition, they were eligible if they spoke English fluently, were able to talk about their experiences with some level of insight and were able to freely provide informed consent. Furthermore, joint agreement was required between the healthcare professional known to the person, the first author, their caregiver, and the individual themselves that they were 'doing okay' or better than expected (Harris 2008; Windle, 2012). People were excluded if they had visual or hearing difficulties

which would have made participation difficult, insufficient level of spoken language, or where English was a second language, were diagnosed with a learning disability, severe depression, psychosis or neurological disorder other than dementia as well as those with a history of head injury or stroke.

Participants were recruited from and with the assistance of two National Health Service (NHS) Scotland Community Mental Health Teams for Older Adults (CMHTOA) located in central Scotland. Members of the CMHTOAs were given verbal and written information (Appendix 4) regarding the study. Potential participants who met eligibility criteria were approached by a healthcare professional from the CMHTOA, who was known to them, and they were invited to participate and given written information (Appendix 5). Further verbal information and a consent form (Appendix 6) was provided by the first author to those who expressed an interest. Participants were given a minimum of 24 hours to consider whether they wished to proceed before arranging an interview at a location of their choice. In addition, the participants' General Practitioner was advised of their decision to participate in the study (Appendix 7). Seven people agreed to be interviewed. The first author discussed the study with one further potential participant however he did not meet eligibility criteria.

All participants were white British, lived in their own home with their spouse or, in one case, their daughter. Participants varied in educational and occupational backgrounds, with academic achievement ranging from primary school attendance to post-graduate degree level. All participants had retired apart from one who continued to contribute to a family business. The participant characteristics are detailed in Table 3.

Table 3 Participant Characteristics

| Participant (Pseudonym) | Gender | Age | Type of dementia | Time since diagnosis (years) | Marital status |
|--|-----------------------------|------------------|-----------------------------|---|---------------------------|
| Jane | Female | 71 | Alzheimer's disease | 0.4 | Married |
| Kate | Female | 74 | Not known | 0.5 | Widowed |
| Moir | Female | 69 | Alzheimer's disease | 0.5 | Married |
| Alan | Male | 82 | Mixed dementia | 1.2 | Married |
| Alice | Female | 82 | Alzheimer's disease | 0.25 | Married |
| James | Male | 80 | Alzheimer's disease | 0.5 | Married |
| David | Male | 82 | Mixed dementia | 0.4 | Married |
| Range | 3 Male, 4 Female | 69-82 | | 0.25-1.2 | |
| Mean (Standard Deviation) | | 77.1(5.7) | | 0.5(0.3) | |

Ethical considerations and consent

Approval for the study was granted by the South East Scotland Research Ethics Committee 01 (Reference: 14/SS/1098; Appendix 8) and the local NHS Scotland Research and Development Department (Appendix 9) prior to commencing the study. All information was protected and stored according to NHS Scotland Code of Practice on Protecting Patient Confidentiality and local NHS Caldicott Confidentiality and Data Protection Policy (Allen, 2014). Informed written consent was obtained from all participants. A process consent method as outlined by Dewing (2007) was employed. This included providing the participant appropriate information to enable them to understand the study and ongoing consent monitoring, reflecting the understanding that capacity is situational and variable. Thus the ability of the participant to provide informed consent was regarded as an ongoing process of

checking and rechecking, rather than a one-off assessment. Although the first author worked within one of the CMHTOAs she was not known to any of the participants prior to the commencement of the study and she was transparent regarding her roles as a trainee clinical psychologist and as a doctoral student. Taking part in the study was voluntary and participants were reminded of their right to stop the interview or to withdraw at any time.

Data Collection

The first author conducted and digitally recorded the in-depth semi-structured interviews within the homes of all participants (Appendix 10). Field notes were recorded before and after the interviews. In addition, reflective memos were written throughout the study as a way of capturing and developing thoughts, ideas, and hypotheses (Charmaz 2014). The importance of memos has been emphasised by Birks and Mills (2011) who described memo-writing as “the most significant factor in ensuring quality in grounded theory” (p. 40). Furthermore, a research journal was kept throughout. Conversation was initiated prior to the interview in order to build rapport and demographic information was collected (Appendix 11). The first author was sensitive to the varying cognitive abilities of the participants, adapting her style accordingly. Participants were given the option to have their caregiver with them during the interview if they wished, however, they were not included in the interview. The interview ended with questions designed to reorientate the participant to time and place. Each participant was interviewed once, with interviews ranging from 23 to 72 minutes, with a mean duration of 42 minutes (standard deviation = 16.3). The first author transcribed the interviews verbatim anonymising the data as required.

Analysis

Data analysis was carried out by the first author in accordance with the methods described by Charmaz (2014). The process involved developing conceptual categories through a process of coding: initially line-by-line, then focussed and finally theoretical. The process was facilitated by constant comparative analysis and reflective memos. Emerging analytical categories were discussed, checked and adjusted through verbal discussions with the second author (Barbour, 2001). This process was repeated until the categories could adequately cope with new data without the need to modify them further - that is when theoretical sufficiency was achieved (Dey, 1999). To ensure internal validity, the first anonymised transcript was cross-coded by a clinical psychologist experienced in the grounded theory methodology outlined by Charmaz (2014) and multiple coding (Barbour, 2001). In addition, themes were cross-validated through a second literature review.

Results

This study proposes a model of how participants have overcome their diagnosis of dementia and continue to live successful, meaningful, and largely unchanged lives (Figure 1.). The model emphasises the maintenance of a sense of normality and continuity between the pre- and post-diagnostic self with participants continuing, and striving, to live their lives with dementia in a way which was consistent with the way they lived their lives prior to their diagnosis. For participants, continuing to live as usual was achieved through a complex interaction of their approach to life and their acceptance of dementia in conjunction with their ability to draw on new and existing social support as well as the support provided by marriage.

OVERCOMING DEMENTIA

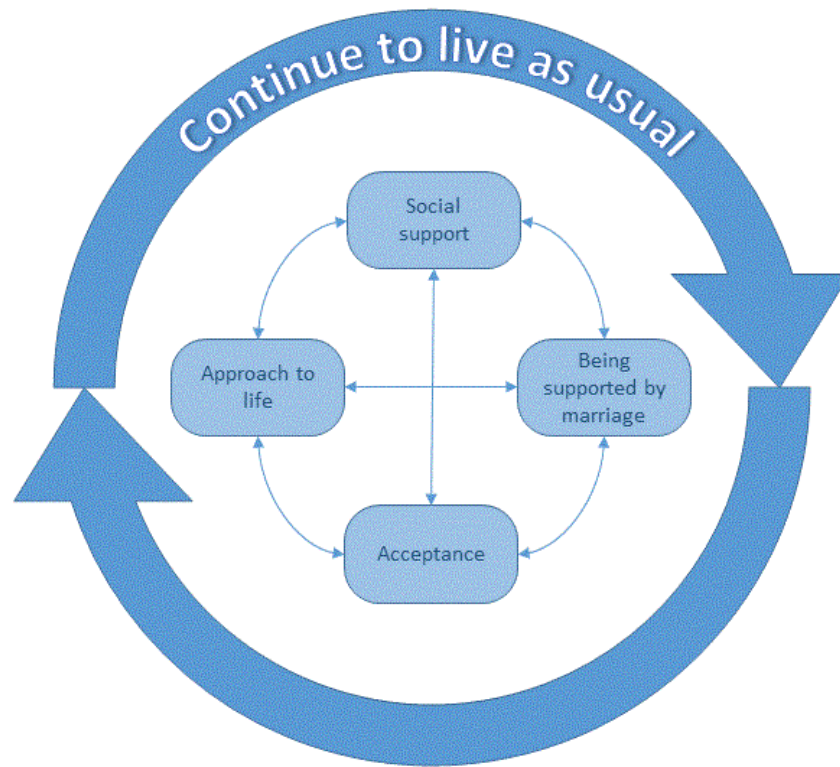


Figure 2 The process of overcoming dementia

Overcoming dementia

The overall core theoretical category was identified as 'Overcoming dementia'. This category captured the structures and processes enabling participants to live successfully with dementia. Within the model of 'Overcoming dementia' five subcategories were identified: 'Approach to life', 'Acceptance', 'Being supported by marriage', 'Social support' and 'Continuing to live as usual'.

Table 3 Overview of conceptual categories

| Category | Themes |
|-----------------------------|--|
| Approach to life | <i>Personal beliefs</i> <i>Life goes on</i> <i>Being determined</i> <i>Being positive</i> <i>Being open about dementia</i> |
| Acceptance | <i>Living in the present</i> <i>Accommodating reduced abilities</i> |
| Being supported by marriage | <i>Marriage as a source of positive emotions</i> <i>Being part of a team</i> <i>Being dependent on husband/wife</i> |
| Social support | <i>Personal relationships</i> <i>Attending groups</i> |
| Continuing to live as usual | <i>Being unchanged by dementia</i> <i>Dementia is not on my mind all the time</i> |

Approach to life

The participants conveyed different aspects of their approach to life which enabled them to live well with dementia and from the description of their experiences five themes were developed within this category: ‘*Personal beliefs*’, ‘*Life goes on*’, ‘*Being determined*’, ‘*Being positive*’ and ‘*Being open about dementia*’.

Personal Beliefs

Participants expressed a range of personal beliefs. Many believed that thinking about dementia was unhelpful:

...if I sat here every day thinking about it, that I have got it, it wouldn't be worth living.

(Kate)

In addition, religious beliefs were considered important:

Well, I just couldn't live without my faith. I just couldn't live without my faith, no.

(Alice)

While many considered themselves to be fortunate and this was often discussed in relation to others who were perceived as less fortunate:

There are a lot of people who just sit under things. I'm not like that. I have had a few hard knocks but you just ...I'm fortunately lucky. I just get on with life. (Moir)

The source of their current beliefs and approach to life was identified by participants as their family, especially their parents, life events, and their religious upbringing:

I just think I took that from my mum. She said 'you are just as well taking it day by day'. (Kate)

I just get on with life...When I lost my... Woke up and my baby was dead. It was quite hard. Then the second one died so it was quite hard about that. And then I just went back to work. (Moir)

I was always brought up to attend church. (Kate)

Life goes on

Often the participants expressed the attitude that 'life goes on' and said this was achieved by 'just getting on with it', 'just carrying on', and 'just keeping going':

Well as just I said before, you just get on with it...try and get on with it. That's what you have been dealt with. (Moir)

So I have adopted the attitude that I am going to lead my life as I would normally do, whatever I can do. So I'm just going along naturally happy with [Wife] and we go places and we go on holiday and we just carry on. (Alan)

I think that people have got to realise that you've got a problem and you don't know how to solve it and the only thing that you can do is to soldier on. Or else your life becomes meaningless and you can't sit in the house all day long and worry about 'am I going to die tomorrow?' (Alan)

Being determined

Participants described being determined and refusing to 'give in' to dementia as well as striving to continue to do things as well as they could:

Well I think that you've got to say to yourself 'I've got this, I don't know why I've got it but I'm not going to let it spoil my life'. I think that is the biggest thing because you can't allow these things to do that to you. (Alan)

I just think it's made me more determined. I just, I said to [Wife] straight away, I said 'I'm not giving in. I'm going to live my life. We're going to live our life.' (Alan)

I just get on with it, I just make the most of what I can do, things I can do, I try to do them to the best of my ability. (Jane)

Being positive

Many participants reported being positive and cheerful:

It doesn't get me down. I'm very positive and I look for easy ways to do everything rather than difficulties put in my way. (Alice)

And I can laugh at things all the time so I mean I don't worry the same as what I used to do. (Moira)

Being open about dementia

Most participants were open about their diagnosis of dementia and described sharing their diagnosis with others in positive terms, saying they found it helpful and in some cases, it mitigated their anxiety.

... anywhere I go, I, the first thing I, most of the time, the first thing I do is tell them that I do have dementia. Some people, in fact, two days ago I met a lady in the village and I told her and she said 'I've had it for years' and was very cheerful about it. (James)

Interviewer: *You said telling people has made you feel calmer*

Moira: *Yes, I know I'm safe. If I need anybody they are there, if they are there.*

Acceptance

Acceptance was described by participants as an important aspect of living with dementia:

But I don't go on every day about thinking (..) 'I've got dementia' because I've got it, well you just have to (.) accept things. (Kate)

The description of the participant's experiences led to the development of two main themes within this category: 'Living in the present' and 'accommodating reduced abilities'.

Living in the present

Participants described taking life as it comes on a day to day basis, with some conveying awareness of being present in the moment, and not making predictions about the future:

I just take days that come. (Kate)

And we forget that we're there for a reason. We're there just because it's a beautiful day and we're in beautiful sunshine and there's beautiful trees and we will walk down.

(Alan)

I don't know what I'll be like further on in the dementia. (Kate)

In addition, a theme emerged of participants becoming a better person as a consequence of their diagnosis. This ranged from treating other people better, being a better husband, being more tolerant of others, to being more compassionate towards others:

Well, I try to be more understanding of people that's not so well. You have to think about, you know, when you're well you didn't think about these things. (Jane)

Furthermore, participants identified changing priorities as part of living in the present:

Interviewer: *So it sounds like there are things that you want to do that are more important than doing the hoovering?*

Moir: *Yes.*

Interviewer: *So the hoovering can wait.*

Moir: *That's right.*

Interviewer: *And there's other things...*

Moira: *Everything can wait.*

Accommodating reduced abilities

As part of their acceptance of dementia participants acknowledged their reduced abilities, described adjusting to them, and adopted coping strategies:

Recognition that one is not as capable as one would like to be I suppose. Yes, that's the mental equivalent of not being able to run after a bus or walk long distances. You just have to ease off. (David)

Adopting coping strategies was a way in which participants were able to adjust to their reducing abilities. Participants described engaging in activities and keeping occupied as particularly helpful with some identifying this reduced worrying:

So we're trying to fill our life with things to do rather than saying 'I wonder if I'm going to get any worse? When is it going to happen? When is the time going to come when I can't do this and I can't do that?' (Alan)

Being supported by marriage

Six of the seven participants in the study were married and living with their spouse and they all considered their husband/wife to be their greatest source of support:

Just in being there with me. Being there for me. (Alice)

Three main themes were developed within this category; *'Marriage as a source of positive emotions'*, *'Being part of a team'*, and *'Being dependent on husband/wife'*.

Marriage as a source of positive emotions

Participants explained marriage made them feel better in a number of ways. Their husband/wife was often a source of reassurance:

It feels safe. I have nothing to...because when I get... He says 'Don't apologise all the time'. (Margaret)

Marriage was also a source of pleasure:

...she's my friend and she's my pal. And she's a business... business person. And she's just fantastic. And we love to do things together. And we have fun. (Alan)

The participant's husband/wife was often described as a reason to continue living:

...and you can't do that because you've got nothing to live for. I have [wife] to live for. (Alan)

Knowing that their husband/wife was there for them provided a source of increased self-esteem:

I get strength from [husband] being there. (Moir)

Interviewer: *what does it mean that he's there to help you?*

Jane: *It makes me more confident in myself.*

Being part of a team

Often participants expressed being part of a team:

We've always been a close couple but we're even closer now than we were because we're a team. (Jane)

Which was characterised by enduring relationships in which both parties knew each other well and participants described their spouse as having positive qualities:

And uh doesn't get too annoyed when I forget that we're meant to be going out to go and meet somebody or do shopping or anything like that. (David)

One aspect of being part of a team was deciding together how to live with dementia:

...we've tried to almost say 'there's nothing wrong with us. There's nothing wrong with me. And I'll just carry on.' Well, obviously that's not true but... (Alan)

A further aspect was not just doing things together but participants describing their husband/wife as accommodating their reduced abilities and facilitating activities:

And [Wife] keeps these things going for me so that we're not sitting at home all the time and looking out the window. (Alan)

Being dependent on husband/wife

Participants acknowledged they relied heavily on their husband/wife for practical, emotional support and memory support:

She looks after me as a carer if you like in a way but not to the extent of, I can dress myself and do things like that. I suppose, I'm not sure what would happen if she wasn't here. I tend to, I wouldn't like to be a week trying to cook my own meals or anything like that (laughs). (David)

Well, he's just there and if I get worked up about a thing he keeps me calm and that, you know... (Jane).

Well I mean [Wife] keeps me right on, sometimes I forget that I haven't taken my tablets and I haven't taken this and I haven't taken that but [Wife] keeps me on an even keel... (Alan)

In addition, some participants expressed concern about the impact of the amount of support their husband/wife was providing

I feel that if she keeps on going at the rate she's going that something will happen with her health. (James)

Social support

Differing forms of relationships were identified as sources of practical and emotional support. The main themes developed within this category were: 'Personal relationships' and 'Attending groups'. A further theme - 'Relationships with professionals' was developed, however, it did not constitute a main theme and will therefore not be discussed here.

Personal relationships

Participants often spoke of being supported by family relationships, friendships, and neighbours. Relationships with children were described as a source of support and were characterised as positive and with regular contact:

We have always been a close sort of family and I think they still feel that way. (Jane)

And I've said to her (wife) 'well don't worry about me because I'll have [Son], my son, with me' because he comes in regularly to see us. (Alan)

In addition, relationships with children were described as a source of reassurance:

[Daughter] said she would come in and see me after lunch, which is what she often does, pops in, and I'm alright if I know somebody is coming. If I know that I've got somebody to come in at the middle of the day or that, I'm alright. I'm alright on my own then. (Jane)

Furthermore, participants enjoyed being in the company of their grandchildren and these relationships were described as a source of positive emotions:

I just enjoy their company and they're cheerful and they make you laugh and that. (Jane)

And he (son) comes to visit us very much. And so I keep in touch with him. And he's got a wee boy and you know. And it's magical. (Alan)

Maintaining friendships was considered important:

Interviewer: *So has it in your experience, what has been helpful or useful to you about sharing your diagnosis with other people?*

James: *Well if I didn't I would be talking to myself. It's essential that I keep my friends.*

Interviewer: *What gives you the ability to keep going?*

Margaret: *People themselves, I have friends that help me through.*

Furthermore, relationships with neighbours were highlighted as a source of support. With participants describing being open with them about their diagnosis of dementia and considering them to be a reliable source of support:

Interviewer: *And how was that, telling the neighbours?*

Moira: *Brilliant. They are all good. They look out for you. You know what I mean and that. They are great neighbours. Just how it used to be years ago.*

Jane: *...I do have neighbours that are reliable as well. That I can go, and if they're there they'll help, you know, if I need any help.*

Interviewer: *And what does it mean to you that you have them there as well?*

Jane: *It gives me more confidence. I know that if I'm here myself I've got somebody I can go for, you know if I need any help but I've never needed to go for anything.*

Attending groups

A few participants reported finding attending non-dementia related groups, such as the Co-operative Women's Guild, church-related groups, and leisure groups as beneficial, however, this did not represent a main theme. Most participants were attending one or more groups

created for people with dementia; a cognitive stimulation group (CST), a woodland activity group, and a peer support group comprising participants who had completed a structured, information-based, dementia post-diagnostic support group (this group was not facilitated by a professional).

Participants highly praised the groups and described benefitting from social interaction within them:

Now, I found it helpful because the people come to that. Now some of them just sit and lean against a tree and they are just there. And, 'do you want a cup of tea?', 'Yeah I'd like a cup of coffee. Could I have a cup? And we bring food and we use the communal food and we spread it out. And we are all sitting chatting to each other. Now, it might be what's going to be on at the pictures next week. Or shall we just have a walk through the woods and just look at the tree and listen to the birds. And I think that is an excellent thing. It really is excellent. (Alan)

Being with people 'in the same boat' was deemed particularly beneficial by the participants and this also afforded opportunities to learn from others in the same situation:

Jane: Well, we've met different people and they're all in the same boat as myself. So they tell us how they manage to cope with it just like, you know, say 'Oh yes, we manage to do things and keep going and you know.

Interviewer: And how is that helpful?

Jane: Well, it makes you feel as if you are in, you're not alone doing anything you've got company and you've got people that you can ask for help if you need help, you know.

The groups were also described as a source of friendship:

I didn't realise that a lot of them for a long time have been living with a husband or a wife but they had been staying, and they didn't know what to do. And so they went out together and then went to the shops and came back home again. This has given them, a group of people who have all become friends and you can say anything to them... (Alan)

In addition, groups were described as a source of fun and laughter:

You feel good when you are sitting there, everybody is the same. You don't need to hold back from anything or feel as if you are out of place. Because we are all the same sitting there. And we just talk about anything and have a laugh. (Moir)

Continuing to live as usual

The participants described continuing to live as usual:

Just go and carry on with life and do what you usually do. (Kate)

Their description of experiences led to the development of two themes within this category:

'Being unchanged by dementia' and 'Dementia is not on my mind all the time'.

Being unchanged by dementia

Participants depicted a life and a sense of self unchanged by their dementia:

Just now, life is just like what I have always had, just now. (Kate)

Well, when I was told that I had dementia, of course, I said 'well that's absolute rubbish. I'm just the same'. I have always been the same. I've still been doing things. I can still go and play sports and I can do this, that, the next thing, go walking. (Alan)

With some expressing an unwillingness to change:

Moira: No, I don't change. I've not changed my life.

Interviewer: Okay.

Moira: I've kept it the way it is.

Dementia is not on my mind all the time

Having dementia was not something the participants reported thinking about all the time:

I don't think I think about dementia if you like as such. (David)

They described avoiding worrying, learning not to worry about dementia, and actively forgetting about dementia:

And for me this has been like a stop in my life and you have got to decide, well I felt I had to decide, do I go into this in great detail and panic and worry in myself or should I just adopt the attitude that I'm, this is my life and I'm going to live it. (Alan)

Interviewer: What's helped you to learn to live with it (dementia)?

David: Trying to learn, learning not to worry too much I think.

Probably my best advice for dementia is to ignore it utterly. (David)

Well, you probably just have to forget you've got it. (Jane)

Discussion

For the participants in this study, resilience was experienced as 'overcoming dementia'. For them, this comprised maintaining a sense of continuity between their pre- and post-diagnostic self and continuing to approach and live life, in the same way, drawing on new and existing support. This was achieved through a complex interaction of their approach to life and their acceptance of dementia in conjunction with social support and the support provided by marriage.

Although participants were aware of their diagnosis and acknowledged their changing abilities, they emphasised normalcy and a life, and sense of self, which was unchanged by dementia. Participants described 'still doing the same things.' However, in many ways they were approaching life and activities differently, adjusting to their reduced abilities and relying on the support of others to facilitate activities. Consistent with this, Williamson and Paslawski (2016) found 'What changed for most participants was *how* they did these activities rather than *what* they did' (p. 11). In addition, Bailey and colleagues (2013) suggest that resilience for people with dementia can 'encompass the ability to continue with established roles and activities that (re)affirm a sense of self and build on a lifelong accumulation of social, knowledge, psychological and material assets' (p. 394). In systematic reviews, 'maintaining normality' was identified by von Kutzleben, Schmid, Halek, Holle and Bartholomeyczik (2012) as a major theme for people living with dementia whilst Bunn and colleagues (2012) highlighted the use of strategies and support to minimise the impact of dementia. Moreover, this study supports the persistence of self and identity reported in other studies (Caddell & Clare, 2010).

Participant's 'approach to life' comprised their personal beliefs, characteristics, and attitudes. As in previous research, being positive or having a positive attitude was evident (Bunn et al., 2012; Harris 2008; Preston, Marshall, & Bucks, 2007; Wiles *et al.*, 2012; Williamson & Paslawski, 2016). Considering themselves as fortunate was consistent with 'counting blessings' (Wiles *et al.*, 2012) and often incorporated self-enhancement through downward social comparisons to others considered less fortunate (Gillies, 2000; Helgeson & Taylor, 1993; Pearce *et al.*, 2002; Sarre et al., 2013) and positive reappraisal coping strategies which allowed them to see their situation from a different, less threatening, perspective (Gross 1998; Lazarus & Folkman 1984). Positive appraisal is considered a key mechanism in resilience by some theorists (Mancini & Bonanno, 2009; Kalisch, Müller, & Tüscher, 2014). The importance of religious beliefs in relation to resilience has been reported (Bauman, Adams, & Waldo, 2001; Harris, 2008; Lee, Brown, Mitchell, & Schiraldi, 2007), with religion enabling older people to attribute a sense of meaning to challenging situations (Coleman, O'Hanlon, & Hanlon, 2004). Although the importance of the ability of older people to draw on religious strength is repeatedly documented in qualitative and quantitative resilience literature it is often absent from resilience measures (van Kessel, 2013). The belief that thinking about dementia is unhelpful may be related to avoidance (Clare, 2002; Gillies, 2000), with Steeman, de Casterle, Godderis, and Grypdonck (2006) identifying the theme of 'not pondering about one's memory deficits' (Clare, 2003; Pearce *et al.*, 2002; Young 2002) as a self-protective strategy. Determination is considered as a defining attribute of resilience (Dyer & McGuinness, 1996) and is consistent with reported themes of fighting against dementia (Cheston, Jones, & Gilliard, 2003; Harris, 2008; Clare, 2002; de Boer et al., 2007; Pearce *et al.*, 2002). Moreover, in their review, de Boer and colleagues (2007) noted that despite the impact of dementia most people continue their lives in the best possible way, identifying the theme 'continue living and fighting back', which bears similarities to 'life goes

on', which encapsulates 'carrying on', 'getting on with it' and 'keeping going'. In a study of resilience in older people with chronic pain, it was 'keeping going' which enabled participants to perceive themselves as well and the authors suggest this may be synonymous with 'doing okay' in defining resilience. For participants in this study, and that of Williamson and Paslawski (2016), being open about their dementia diagnosis contributed to resilience, was considered positive, and was associated with improved wellbeing. This contrasts findings where people with dementia have reported concerns around stigma resulting in social withdrawal and feelings of being excluded (Clarke & Bailey, 2016; Langdon, Eagle, & Warner, 2007). Furthermore, Weaks, Wilkinson, and McLeod (2014) concluded those who found it easier to share their diagnosis were able to draw on a wider range of social resources and were more emotionally resilient.

Participants traced the origins of their beliefs and approach to life to their family, life events, and religious upbringing. This supports findings that personal characteristics related to resilience are embedded within a social context (Wiles *et al.*, 2012) and the notion of 'steeling effects' (Rutter, 1999) whereby effective negotiation of adversity earlier in life facilitates a resilient response later.

As in previous studies (Harris, 2008; Williamson & Paslawski, 2016), acceptance was found to be a salient aspect of resilience in people with dementia. Furthermore, themes of accepting dementia in conjunction with fighting against dementia have consistently been reported (Cheston *et al.*, 2003; Clare, 2002; Harris, 2008; Pearce *et al.*, 2002; Preston *et al.*, 2007). In older people more generally, acceptance of self and life is considered a key characteristic of resilience (van Kessel, 2013, Waginald & Young, 1993), with research suggesting that self-acceptance becomes more prominent as people age and is important to positive psychological functioning (Ryff & Singer, 1996). Accepting limitations is part of the process

of accommodating negative aspects of ageing while adjusting goals in relation to functional impairments and losses can help maintain a positive self-identity (Brandtstädter & Greve, 1994). Developing coping strategies (Harris, 2008; Williamson & Paslowski, 2016) enables people with dementia to 'compensate' or 'overcome' the effects of their memory difficulties and is related to adjustment and coping along with 'coming to terms' with them (Clare, 2002). In 'changing priorities', there is evidence of selection, in relation to reconstructing values and goals in response to loss, and compensation (see Baltes & Baltes, 1990). 'Living in the present' is a theme identified in previous studies of people with dementia (Bunn *et al.*, 2012). While 'becoming a better person' is perhaps at odds with public perception of dementia, 'personal growth' has been established within this population (Kitwood, 1995) and is one of the six domains of resilience identified by Rhyff (1985).

Being supported by marriage was a main category in this study, although in other studies this has been subsumed to more generic 'support' categories (Harris, 2008; Williamson & Paslowski, 2016). Research on spousal relationships is largely from the perspective of the spouse rather than the person with dementia (Molyneaux, Butchard, Simpson, & Murray, 2011) and often from the position of 'burden' (Montgomery & Williams, 2001), which has been criticised for failing to capture the dynamics of couplehood in dementia (Hellstrom, Nolan, & Lundh, 2007). Kaplan (2001) constructed a typology of five kinds of relationships underpinned by couplehood, defined as the extent to which there was a sense of 'we' in the relationship, as opposed to increasing distance and a sense of 'I'. According to this model the experiences of participants was consistent with the first typology 'Til death us do part' as there was still a very strong sense of 'we', which largely defined their lives. One aspect of 'being part of a team' was spousal accommodation of reduced abilities and the facilitation of activities which bore similarities to 'maintaining involvement' (Hellstrom *et al.*, 2007) where

activities are initially shared but are increasingly initiated by the spouse. Reliance on a spouse is considered a self-protective strategy (Steeman *et al.*, 2006) and has been related to efforts to maintain a prior sense of self (Pearce *et al.*, 2002). For older people, dependency continues to be perceived as a negative outcome, however, it can provide additional protective factors, for example, it can make available resources for new social connections and other activities and can reduce the stress associated with the management of everyday life (Staudinger, Marsiske, & Baltes, 1993). The importance of marriage, and indeed other relationships, in supporting the self-esteem of participants supports theoretical models of dementia which emphasise the importance of environment, such as Kitwood's (1990) person-centred care model, Sabat's (2001) social constructionist theory, and Van Dijkhuizen and colleagues' (2006) level of connectedness model.

As in other studies of resilience in older people social support is emphasised, participants relied on family, friends, and neighbours for socialising and emotional and practical support (Hildon *et al.*, 2008). Family support has been emphasised in resilience studies of those with dementia (Harris, 2008; Williamson & Paslowski, 2016) while being valued by family and friends is central to the experience of living with dementia (Steeman, Godderis, Grypdonck, De Bal, & De Casterlé, 2007). These findings contrast with those where a theme of isolating oneself from others was evident (Ostwald, 2002; Snyder, 2002; Werezak & Stewart, 2002).

In the current study social support encompassed relationships forged and maintained through the attendance of both facilitated and non-facilitated dementia groups, with participants emphasising the importance of solidarity, peer support (Bunn *et al.*, Harris, 2008, Keyes *et al.*, 2016; Wiersma *et al.*, 2016, Williamson & Paslowski, 2016), positive experiences and feelings (Spector, Gardner, & Orrell, 2011). This is consistent with the finding that older people with resilient outcomes draw on a broader range of not just individual but social

resources (Hildon *et al*, 2008). Furthermore, attending support groups has been described as an integrative strategy, whereby people face up to the threats of dementia and aim to deal with them (Steeman *et al.*, 2006).

Strengths and Limitations

The current study contributes to the very limited research of resilience in those living with mild to moderate dementia and proposes a model of resilience within this population. The majority of existing research on dementia has focussed on medical and cognitive aspects and the impact on caregivers, with limited research on the experiences of the person with dementia (Johannessen & Moller, 2011). This study shows that people with dementia, in spite of their cognitive impairment and memory loss are able to speak about their experiences of living with dementia and what it is that enables them to live well with it. Indeed, most said they found being given the opportunity to talk about their situation and their own experiences of dementia helpful, enjoyable, or therapeutic.

Overall the current findings support a biopsychosocial model of dementia (Spector & Orrell, 2010), rather than a medical/biological approach, and furthermore advocates a model of resilience which incorporates not only individual and environmental aspects such as social, community, societal and cultural, but also the individual's ability to draw on these resources. Furthermore, the current conceptualisation of resilience, with both fixed and tractable factors (Spector & Orrell, 2010), opens up the future possibility of promoting resilience through the development of psychosocial interventions.

Some limitations should be acknowledged. Bias is likely to have been introduced by the recruitment process and characteristics of the people who agreed to participate may differ

from those who would have chosen not to. The findings are a co-construction between a small sample of participants and the researcher and are therefore not broadly generalisable. Moreover, these findings relate to a particular time-frame and do not reflect potential changes in coping or resilience over time, which could be the subject matter of future longitudinal studies. People with dementia rate their quality of life more positively than their caregivers (Thorgrimsen et al., 2003) and it is possible caregiver perspective may differ. Although the current study was primarily interested in the experience of the person with dementia, triangulating interview data from participants with that from caregivers may provide useful insights into subconscious coping strategies. Furthermore, this study focussed on protective factors and future investigations of vulnerability factors will build on the current understanding of resilience in people with dementia.

Conclusion

The model, 'Overcoming dementia', emphasises the importance of continuity of self and maintaining normality, 'continuing to live as usual', which is achieved through the complex interaction of approach to life and acceptance of dementia in conjunction with social support and the support provided by marriage. This study evidences the achievability of resilience and continuing to live well despite a diagnosis of dementia, with future research into the concept of resilience warranted. Furthermore, the finding both internal and external factors contribute to resilience opens up the possibility of intervention development to promote resilience in people with dementia.

Finally, this study emphasises not only the strengths and abilities of people with dementia, and the importance of social support, but the possibility of continuing to experience life in a way that is perhaps less affected by dementia than might be presumed. It is important to

communicate such research in order to develop a more accurate and positive understanding of dementia and challenge largely held preconceptions.

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Appendix 1.

Manuscript guidelines for journal *Dementia*

Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

1. Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

1.1 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2. Article types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

The journal also publishes book reviews.

3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Dementia is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne[®] Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

IMPORTANT: If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the '[Online Help](#)' button at the top right of every screen.

All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

Innovative Practice papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty jo.moriarty@kcl.ac.uk.

Books for review should be sent to: Book Review Editor ♦ *Dementia*, Heather Wilkinson, College of Humanities & Social Science, University of Edinburgh, 55-56 George Square, Edinburgh, EH8 9JU, UK. Email: hwilkins@staffmail.ed.ac.uk

4. Journal contributor's publishing agreement

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Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the

journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

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5. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. It is the policy of *Dementia* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please include any declaration at the end of your manuscript after any acknowledgements and prior to the references, under a heading 'Declaration of Conflicting Interests'. If no declaration is made the following will be printed under this heading in your article: 'None Declared'. Alternatively, you may wish to state that 'The Author(s) declare(s) that there is no conflict of interest'.

When making a declaration the disclosure information must be specific and include any financial relationship that all authors of the article has with any sponsoring organization and the for-profit interests the organization represents, and with any for-profit product discussed or implied in the text of the article.

Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Declaration of Conflicting Interests provided in the article.

Please acknowledge the name(s) of any medical writers who contributed to your article. With multiple authors, please indicate whether contributions were equal, or indicate who contributed what to the article.

For more information please visit the [SAGE Journal Author Gateway](#).

6. Other conventions

6.1 Informed consent

Submitted manuscripts should be arranged according to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". The full document is available at <http://icmje.org>. When submitting a paper, the author should always make a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.

Ethical considerations: All research on human subjects must have been approved by the appropriate research body in accordance with national requirements and must conform to the principles embodied in the Declaration of Helsinki (<http://www.wma.net>) as well as to the International Ethical Guidelines for Biomedical Research Involving Human Subjects and the International Guidelines for Ethical Review for Epidemiological Studies (<http://www.cioms.ch>). An appropriate statement about ethical considerations, if applicable, should be included in the methods section of the paper.

6.2 Ethics

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Declaration of Helsinki 1975, revised Hong Kong 1989. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate which guideline/law on the care and use of laboratory animals was followed.

7. Acknowledgements

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

7.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), *Dementia* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit [Funding Acknowledgement](#) on the SAGE Journal Author Gateway for funding acknowledgement guidelines.

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9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, DOCX, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

9.2 Journal Style

Dementia conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

Lengthy quotations (over 40 words) should be displayed and indented in the text.

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dementers). Language that might be deemed sexist or racist should not be used.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

9.3 Reference Style

Dementia adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

9.4. Manuscript Preparation

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words.

9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#). The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

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This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

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10.1 Proofs

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11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office at dem.pra@sagepub.com.

Appendix 2

Downs and Black Checklist (1998) for measuring study quality, including amendment to question 27.

| Reporting | | | |
|------------------|---|------------------------------------|--|
| 1. | <i>Is the hypothesis/aim/objective of the study clearly described?</i> | yes = 1 no = 0 | |
| 2. | <i>Are the main outcomes to be measured clearly described in the Introduction or Methods section?</i> If the main outcomes are first mentioned in the Results section, the question should be answered no. | yes = 1 no = 0 | |
| 3. | <i>Are the characteristics of the patients included in the study clearly described?</i> In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given. | yes = 1 no = 0 | |
| 4. | <i>Are the interventions of interest clearly described?</i> Treatments and placebo (where relevant) that are to be compared should be clearly described. | yes = 2 no = 0 | |
| 5. | <i>Are the distributions of principal confounders in each group of subjects to be compared clearly described?</i> A list of principal confounders is provided. | yes = 1 partially = 2 no = 0 | |
| 6. | <i>Are the main findings of the study clearly described?</i> Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below). | yes = 1 no = 0 | |
| 7. | <i>Does the study provide estimates of the random variability in the data for the main outcomes?</i> In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes. | yes = 1 no = 0 | |
| 8. | <i>Have all important adverse events that may be a consequence of the intervention been reported?</i> This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided). | yes = 1 no = 0 | |
| 9. | <i>Have the characteristics of patients lost to follow-up been described?</i> This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up. | yes = 1 no = 0 | |

| | | | |
|---|---|--|--|
| 10. | <i>Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?</i> | yes = 1 no = 0 | |
| External validity All the following criteria attempt to address the representativeness of the findings of the study and whether they may be generalised to the population from which the study subjects were derived. | | | |
| 11. | <i>Were the subjects asked to participate in the study representative of the entire population from which they were recruited?</i> The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine. | yes = 1 no = 0 unable to determine = 0 | |
| 12. | <i>Were those subjects who were prepared to participate representative of the entire population from which they were recruited?</i> The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population. | yes = 1 no = 0 unable to determine = 0 | |
| 13. | <i>Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?</i> For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend. | yes = 1 no = 0 unable to determine = 0 | |
| Internal validity - bias | | | |
| 14. | <i>Was an attempt made to blind study subjects to the intervention they have received?</i> For studies where the patients would have no way of knowing which intervention they received, this should be answered yes. | yes = 1 no = 0 unable to determine = 0 | |
| 15. | <i>Was an attempt made to blind those measuring the main outcomes of the intervention?</i> | yes = 1 no = 0 unable to determine = 0 | |
| 16. | <i>If any of the results of the study were based on "data dredging", was this made clear?</i> Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes. | yes = 1 no = 0 unable to determine = 0 | |
| 17. | <i>In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control</i> | yes = 1 no = 0 | |

| | | | |
|---|--|---|--|
| | <p><i>studies, is the time period between the intervention and outcome the same for cases and controls?</i></p> <p>Where follow-up was the same for all study patients the answer should be yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.</p> | <p>unable to determine = 0</p> | |
| 18. | <p><i>Were the statistical tests used to assess the main outcomes appropriate?</i></p> <p>The statistical techniques used must be appropriate to the data. For example nonparametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.</p> | <p>yes = 1 no = 0 unable to determine = 0</p> | |
| 19. | <p><i>Was compliance with the intervention/s reliable?</i></p> <p>Where there was non compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.</p> | <p>yes = 1 no = 0 unable to determine = 0</p> | |
| 20. | <p><i>Were the main outcome measures used accurate (valid and reliable)?</i></p> <p>For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.</p> | <p>yes = 1 no = 0 unable to determine = 0</p> | |
| Internal validity – (selection bias) | | | |
| 21. | <p><i>Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?</i></p> <p>For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case control studies where there is no information concerning the source of patients included in the study.</p> | <p>yes = 1 no = 0 unable to determine = 0</p> | |
| 22. | <p><i>Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?</i></p> <p>For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine</p> | <p>yes = 1 no = 0 unable to determine = 0</p> | |
| 23. | <p><i>Were study subjects randomised to intervention groups?</i></p> <p>Studies which state that subjects were randomised should be answered yes except where method of randomisation would not ensure random allocation. For example alternate allocation would score no because it is predictable.</p> | <p>yes = 1 no = 0 unable to determine = 0</p> | |
| 24. | <p><i>Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?</i></p> | <p>yes = 1 no = 0 unable to determine = 0</p> | |

| | | | |
|--|--|--|--|
| | All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no. | | |
| 25. | <p><i>Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?</i></p> <p>This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In nonrandomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.</p> | <p><i>yes = 1</i> <i>no = 0</i> <i>unable to determine = 0</i></p> | |
| 26. | <p><i>Were losses of patients to follow-up taken into account?</i></p> <p>If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.</p> | <p><i>yes = 1</i> <i>no = 0</i> <i>unable to determine = 0</i></p> | |
| Power | | | |
| 27. | Did the study report a power or sample size calculation? | <p><i>yes = 1</i> <i>no = 0</i></p> | |
| Total quality score (max possible = 28) | | | |

Appendix 3

Data Extraction Form

Date of extraction:

Reviewer: Gillian Bailey

| General information | |
|-------------------------------------|--|
| <i>1st author</i> | |
| <i>Title</i> | |
| <i>Year</i> | |
| <i>Country</i> | |
| Study Characteristics | |
| <i>Aim or hypotheses</i> | |
| <i>Design</i> | |
| Participant characteristics | |
| <i>Sample size</i> | |
| <i>Demographic variables</i> | Mean age (SD): Male: Female: Education: Cognitive functioning: |
| <i>Population description</i> | |
| Methods | |
| <i>Recruitment</i> | |
| <i>Inclusion/exclusion criteria</i> | |
| <i>Intervention</i> | |

| | |
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| | |
| <i>Measure of cognition</i> | |
| <i>Follow-up</i> | |
| <i>Attrition and completion rates (withdrawals and exclusions)</i> | |
| <i>Missing data</i> | |
| Main statistical analyses | |
| | |
| Outcomes/Results | |
| | |
| Key conclusions | |
| | |
| Limitations | |
| | |
| Additional notes | |
| | |



Participant Recruitment Information Sheet

Project Title: Exploring Resilience in People with Dementia: a Qualitative Study
Name of Researcher: Gillian Bailey, Trainee Clinical Psychologist
Forth Valley Older Adult Clinical Psychology Service
Stirling Community Hospital
Stirling
FK8 2AU
Tel: 01786 454665

My name is Gillian Bailey and I am studying for my Doctorate in Clinical Psychology at The University of Edinburgh and I am a Trainee Clinical Psychologist working in the Community Mental Health Team for Older Adults in NHS Forth Valley. I am required to undertake a project as part of my course and I am currently recruiting participants for my study.

What is the purpose of the study?

Resilience is the ability to cope with and adapt to significant challenges. The purpose of the study is to find out more about the experience of resilience in people with a diagnosis of dementia. More information about this may provide a better understanding of the things that promote resilience in people with dementia.

What does taking part involve for the patient?

If your patient participates in the study they will be asked some basic background information (e.g. their age, if they are married or not, and type of dementia (if known) they are diagnosed with), and they will take part in an interview for around an hour. Their carer can be present if they wish.

Confidentiality

All information will be protected and stored according to guidelines – NHS Scotland, NHS Code of Practice on Protecting Patient Confidentiality and NHS Forth Valley Caldicott, Confidentiality and Data Protection Policy. Participants will be fully informed about what will happen with their information during the information giving/consent part of the study.

What are the possible benefits of taking part?

There will be no direct benefits to your patient taking part in the study, but hopefully they will find it interesting. The findings may provide a better understanding of what promotes resilience in people with dementia, the things that help them cope with and adapt to significant challenges. This will help local and wider services better understand the needs of people with dementia.

Page 1 of 3



What will happen to the results of the study?

The results will be available within a year after the study is finished. Reports of the study will be based on interviews with all the people who took part. The reports will describe the experiences of the group of people as a whole and will not identify any individual. The results will be presented to local services and to researchers internationally. If your patient chooses to they will receive a copy of the research findings.

Who is organising and funding the research?

The study is organised by the Doctoral Clinical Psychology Programme at University of Edinburgh. It is supervised by Dr Heather Wilkinson, Director of Research & Knowledge Exchange, School for Health in Social Science, University of Edinburgh, and Dr Matthias Schwannauer, Programme Director and Consultant Clinical Psychologist, and Dr Hazel Connery, Clinical Psychologist. The research is funded by NHS Education for Scotland. If you have any complaints about the research or how it was conducted, please contact Dr Matthias Schwannauer on telephone number 0131 651 3972.

Who has reviewed the study?

The East of Scotland Research Ethics Service REC 1, which is responsible for reviewing proposed studies to protect the dignity, rights, safety and wellbeing of all actual or potential research participants, has examined the proposal and has raised no objections from the point of view of medical ethics. The study has also been fully approved by NHS Forth Valley Research and Development Office. The study will follow standard ethical practice of the British Psychological Society.

Who is eligible to take part in the study?

People can take part if they meet all of these criteria:

- Patients are adults of any age who have attended a memory clinic and received a diagnosis of any type of dementia from a psychiatrist.
- The person has been told their diagnosis and has retained that information.
- The person is considered to be in a sufficiently early stage of the dementia that they are able to talk about their experience with some level of insight.
- The participant is able to freely provide informed consent. (A process consent method, as outlined by Dewing, 2007, will be employed. This includes providing information that is appropriate for the person with dementia to enable them understand the study and ongoing consent monitoring, which reflects the understanding that capacity is situational and variable).
- The carer, healthcare professional and chief investigator (Gillian Bailey) and the patient all self-define the patient as "doing okay" (Harris 2008, Windle 2012)
- Patients who speak English fluently.
- Patients who can see and hear well enough to participate fully.

Page 2 of 3



Unfortunately, if a person meets any of the following criteria they cannot participate:

- Patients who have a diagnosis of a learning disability.
- Patients with severe depression, psychosis, or neuropsychological disorder other than dementia.
- Patients with a history of stroke or head injury.
- Patients with English as a second language or those without sufficient level of spoken English to take part.
- Those assessed by the carer, healthcare professional or chief investigator (Gillian Bailey) as unable to participate.

Confidentiality

All information will be protected and stored according to guidelines – NHS Scotland, NHS Code of Practice on Protecting Patient Confidentiality and NHS Forth Valley Caldicott, Confidentiality and Data Protection Policy. Participants will be fully informed about what will happen with their information during the information giving/consent part of the study.

Where can I get more information?

If you wish to discuss the study further please contact Gillian. If you know a patient who is interested in participating and they would like to discuss the study with Gillian just let her know and she will contact them.



Letter of Invitation to Take Part in Research Study

- The study is about the experience of resilience in people who have a diagnosis of dementia. Resilience is the ability to cope with and adapt to significant challenges.
- The study is being conducted by Gillian Bailey. Gillian is a postgraduate psychology student at Edinburgh University and a Trainee Clinical Psychologist working within the Community Mental Health Team for Older Adults in NHS Forth Valley.
- If you decide to take part in the study you will meet with Gillian for an interview which will last up to an hour.
- Taking part is completely voluntary, anonymous and confidential.
- Deciding whether or not to take part will not affect your usual care.
- There are no direct benefits to taking part in the study but hopefully you will find it interesting.
- Read more about the study in 'The Participant Information Sheet'.

Interested in taking part?

- If you are interested in taking part then tell a member of the Community Mental Health Team for Older Adults. They will arrange for Gillian to contact you so she can tell you more about the study and answer any questions you might have.

**Community Mental Health Team for Older Adults
NHS Forth Valley
Stirling Community Hospital
Stirling
FK8 2AU
Telephone 01786 454665**

Page 1 of 1



Participant Information Sheet

My name is Gillian Bailey and I am studying for my Doctorate in Clinical Psychology at The University of Edinburgh. I am required to undertake a project as part of my course and I am inviting you to take part in my study. However, before you decide to do so I need to be sure you understand why I am doing it and what would be involved if you agreed. I am therefore providing you with the following information. Please read it carefully and be sure to ask any questions you might have. I will do my best to explain the project to you and provide you with any further information you may ask for now or later.

What is the purpose of the study?

Resilience is the ability to cope with and adapt to significant challenges. The purpose of the study is to find out more about the experience of resilience in people with a diagnosis of dementia. More information about this may provide a better understanding of the things that help people with dementia.

Who is doing this study?

I am a psychology postgraduate student at The University of Edinburgh and a Trainee Clinical Psychologist in the Community Mental Health Team for Older Adults in NHS Forth Valley. The study is part of my psychology degree work.

Why have I been asked to take part?

You have been asked to take part as you have a diagnosis of dementia and you have been considered suitable to take part by your health professional within the Community Mental Health Team for Older adults, NHS Forth Valley.

Do I have to take part?

No, taking part in this study is completely voluntary. It is up to you whether or not to take part. You will be given at least 24 hours and up to one month to decide whether or not you would like to take part. If you decide to take part you will be asked to sign a consent form by me. That is a form which confirms you understand what the study entails and are happy to take part. Even if you decide to take part you are still free to leave the study at any time and you do not have to give a reason. Whether or not you decide to take part in the study, or leave the study, will not in any way influence the care (positively or negatively) you receive from the Community Mental Health Team for the Elderly, NHS Forth Valley.

What does taking part involve?

If you take part in the study you will be asked some basic background information (e.g. your age, if you are married or not, and type of dementia you are diagnosed with, if you know) and I will come and talk with you in an interview of about one hour. You can have a friend or relative present if you wish.



In the interview you will be asked to describe your experience of living with dementia and the things that you have found helpful. The interview will be audio recorded and will take place at a time and place convenient to you.

What are the possible disadvantages and risks of taking part?

It is possible you may become upset during the interview and if this happened you can ask for the interview to be stopped. If you require further support this would be put in place with the most appropriate member of the Community Mental Health Team for Older Adults. I would be available in my role as a Trainee Clinical Psychologist to offer further support if required.

What are the possible benefits of taking part?

Participating in this study will give you the opportunity to talk about your experience of dementia, which may find beneficial. Hopefully you will find participating an interesting, enjoyable, and a positive experience.

The findings may provide a better understanding of the things that promote resilience in people with dementia, the things that help them cope with and adapt to significant challenges. This will help local and wider services better understand the needs of people with dementia.

Confidentiality

If you decide to take part you will be asked to consent to your G.P. being notified of your decision to participate. All of the information you give the researcher will be anonymous and confidential, within standard clinical guidelines. That means that the information will not be reported back to the Community Mental Health Team for Older Adults or your G.P. However, if you tell me information that makes me think you or someone else might be at risk of harm, I will have to pass that information on to the appropriate health professional (member of the Community Mental Health Team for Older Adults and/or G.P.).

The information you give in the study will be stored in a secure and anonymous way according to the 'Data Protection Act'. That means that if you take part in the study, you will be given a unique research number. Only this number will be shown in the information stored about you. The recorded interview will be kept in a locked filing cabinet. After the interview has been transcribed (written up) by me, the recording will be deleted. All information you provide will be kept in locked filing cabinets and on password protected computers/secure servers. Only myself and members of the research team will have access to the information.

What will happen to the results of the study?

The results will be available within a year after the study is finished. Reports of the study will be based on interviews with all the people who took part. The reports will describe the experiences of the group of people as a whole and will not identify any individual.



The results will be presented to local services and to researchers internationally. If you would like to, you will receive a copy of the research findings.

Who is organising and funding the research?

The study is organised by the Doctoral Clinical Psychology Programme at University of Edinburgh in partnership with NHS Forth Valley. It is supervised by Dr Heather Wilkinson, Director of Research & Knowledge Exchange, School for Health in Social Science, University of Edinburgh, and Dr Matthias Schwannauer, Programme Director and Consultant Clinical Psychologist, and Dr Hazel Connery, Clinical Psychologist. Gillian Bailey is salaried by NHS Forth Valley. If you have any complaints about the research or how it was conducted, please contact Dr Matthias Schwannauer on telephone number 0131 651 3972.

Who has reviewed the study?

A research ethics committee (REC), which is responsible for reviewing proposed studies to protect the dignity, rights, safety and wellbeing of all actual or potential research participants, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Edinburgh and NHS Forth Valley, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected. The study has also been fully approved by NHS Forth Valley Research and Development Office.

Where can I get more information or sign up for the study?

If you are interested in hearing more about the study please tell a member of the Community Mental Health Team for Older Adults, NHS Forth Valley. He/she will contact me and then I will contact you.

**Community Mental Health Team for Older Adults
NHS Forth Valley
Stirling Community Hospital
Stirling, FK8 2AU
Telephone: 01786 454665 email: gillianbailey2@nhs.net**

If you would like to discuss this study with someone independent of the study team please contact Dr Jenny Svanberg, Consultant Clinical Psychologist on telephone number: 01786 434433 or email: jenny.svanberg@nhs.net

If you wish to make a complaint about the study please contact NHS Forth Valley:

**NHS Forth Valley Patient Relations and Complaints Service
Forth Valley Royal Hospital
Stirling Road, Larbert
FK5 4WR
Telephone: 01324 566660 or email: fv-uhb.complaints@nhs.net
Page 3 of 3**

Appendix 6



Project Title: Exploring Resilience in People with Dementia: a Qualitative Study

Name of Researcher: Gillian Bailey, Trainee Clinical Psychologist
Forth Valley Older Adult Clinical Psychology Service
Stirling Community Hospital
Stirling
FK8 2AU
Tel: 01786 454665

Thank you for reading the information about our research project. If you would like to take part, please read and sign this form.

Participant's name: _____

Please initial

1. I have read and understand the information sheet (version 1, 9.11.14) and have had the opportunity to ask questions. _____
2. I understand that taking part is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. _____
3. If I get upset during the interview, I can ask for the interview to be stopped. I can also ask to speak to the researcher at a later date if I would like to discuss anything I talked about during the interview. _____
4. All the information I provide in the study will be anonymous and confidential. However, if I reveal information about future harm to myself, or others, that information will be passed onto the appropriate healthcare professional. _____
5. I give permission for my G.P. to be informed of my participation and given any relevant information. _____
6. I understand the interviews will be recorded and typed word for word. I give permission for this to be done. _____

Page 1 of 2



7. I understand that direct quotes may be used in future publications, but will be anonymised (that is, they will not be traceable to me). _____
8. I understand the recordings will be destroyed once the interviews have been analysed. _____
9. I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsor (university of Edinburgh) or from NHS Forth Valley, where it is appropriate. I give permission for those individuals to have access to my data. _____
10. I agree to take part in the above study. _____

Name of participant Signature Date

Name of person taking consent Signature Date

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.

Appendix 7



Our Ref:

Older Adult Clinical Psychology Service
Community Mental Health Team for Older Adults
Stirling Community Hospital
Livlands Gate
Stirling
FK8 2AU
Tel: 01786 454667

DATE

PRIVATE AND CONFIDENTIAL

Dr
GP Address

Dear Dr

Re:

The above named patient has agreed to participate in a research study: "Exploring Resilience in People with Dementia: a Qualitative Study". The study is carried out by NHS Forth Valley in collaboration with The University of Edinburgh. I have enclosed a copy of the participant information form.

The purpose of the study is to find out more about the experience of resilience in people with a diagnosis of dementia. More information about this may provide a better understanding of what promotes resilience in this population.

Your patient will participate in a semi-structured interview, lasting approximately one hour, and there will be no change to the management and treatment of your patient. This study does not involve Investigational Medicinal Product. If you require any further information please do not hesitate to contact me.





Yours sincerely

Gillian Bailey
Specialist Psychology Practitioner

Dr Hazel Connery
Chartered Clinical Psychologist

Page 1 of 1

Appendix 8

| | | |
|---|--|--|
| Lothian NHS Board | South East Scotland Research Ethics Committee 01 |  |
| | Waverley Gate 2-4 Waterloo Place Edinburgh EH1 3EG Telephone 0131 536 9000 www.nhslothian.scot.nhs.uk | |
| Mrs Gillian Bailey Trainee Clinical Psychologist NHS Forth Valley Community Mental Health Team for Older Adults Stirling Community Hospital Livlands Gate Stirling FK82AU | Date: 19 December 2014 Your Ref: Our Ref: Enquiries to: Sandra Wyllie Extension: 35473 Direct Line: 0131 465 5473 Email: Sandra.Wyllie@nhslothian.scot.nhs.uk | |
| Dear Mrs Bailey | | |
| Study title: | Exploring Resilience in People with Dementia: a Qualitative Study | |
| REC reference: | 14/SS/1098 | |
| Protocol number: | n/a | |
| IRAS project ID: | 153703 | |
| <p>Thank you for your letter of 18 December 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.</p> <p>The further information has been considered on behalf of the Committee by the Chair.</p> <p>We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Sandra Wyllie, sandra.wyllie@nhslothian.scot.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.</p> <p>Confirmation of ethical opinion</p> <p>On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.</p> <p>Conditions of the favourable opinion</p> <p>The favourable opinion is subject to the following conditions being met prior to the start of the study.</p> | | |
|  INVESTORS IN PEOPLE |  SCOTTISH SPIRIT |  Healthy Working Lives |
| <p>Headquarters Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG Chair Mr Brian Houston Chief Executive Tim Davison <i>Lothian NHS Board is the common name of Lothian Health Board</i></p> | | |

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|--|---------|------------------|
| Covering letter on headed paper [Response to PO Letter] | | 18 December 2014 |
| Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) [PL_Confirmation_9.11.14_1] | 1 | 09 November 2014 |
| GP/consultant information sheets or letters [GP_letter_9.11.14[1]] | 1 | 09 November 2014 |
| Interview schedules or topic guides for participants [GT_Interview_questions_9.11.14[1]] | 1 | 09 November 2014 |
| Letters of invitation to participant [Letter_of_Invitation_to_Take_Part_In_Research_Study_12.12.14[2]] | 2 | 12 December 2014 |
| Other [Demographics_Data_Sheet_9.11.2014[1]] | 1 | 09 November 2014 |
| Other [Participant_recruitment_information_form_9.11.14[1]] | 1 | 09 November 2014 |
| Other [CV_Matthias_Schwannauer_9.11.14_1] | 1 | 09 November 2014 |
| Other [CV_Hazel_Connery_9.11.14_1] | 1 | 09 November 2014 |
| Participant consent form [Consent_form_9.11.14[1]] | 1 | 09 November 2014 |
| Participant information sheet (PIS) [Participant_Information_Sheet_12.12.14[2].doc] | 2 | 12 December 2014 |
| REC Application Form [REC_Form_19112014] | | 19 November 2014 |
| Research protocol or project proposal [Thesis_research_proposal_Gillian_Bailey_9.11.14[1]] | 1 | 09 November 2014 |
| Summary CV for student [CV_Gillian_Bailey_9.11.14_1] | 1 | 09 November 2014 |
| Summary CV for supervisor (student research) [CV_Heather_Wilkinson_9.11.14_1] | 1 | 09 November 2014 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

| | |
|------------|--|
| 14/SS/1098 | Please quote this number on all correspondence |
|------------|--|

With the Committee's best wishes for the success of this project.

Yours sincerely




Dr Janet Andrews
Chair

Email: sandra.wyllie@nhslothian.scot.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Rosemary Wilson, NHS Forth Valley

Appendix 9

| | | |
|--|---|---|
| CAL/0000205 | NHS FORTH VALLEY CALDICOTT / DATA PROTECTION CONSENT FORM |  |
| APPROVAL FOR THE RELEASE OF NON-ANONYMISED INFORMATION WITHOUT CONSENT | | |
| Data Source (enter details of system): Interviews with patients. | | |
| Reason for Request: Research project – Exploring Resilience in People with Dementia | | |
| Time Period for request: Start Date: 01/01/2015 End Date: 31/12/2015 | | |
| Intended Recipients Details | | |
| Name: | Gillian Bailey | |
| Position: | Trainee Clinical Psychologist | |
| Organisation: | NHS Forth Valley/The University of Edinburgh | |
| Address: | Forth Valley Older Adult Clinical Psychology Service, Stirling Community Hospital, Stirling, FK8 2AU. | |
| Tel. No: | 01786 454665 or 07719658892 | |
| Email Address: | gillianbailey2@nhs.net | |
| Data Protection Registration No. | NA | |
| Name(s) of any co-user(s): | Anonymised transcripts may be accessed by Professor Heather Wilkinson, Professor Matthias Schwannauer, The University of Edinburgh, or Dr Hazel Connery, Clinical Psychologist NHS Forth Valley, in their role as supervisor. | |
| Data Remaining within UK: | Yes | |
| Will the Data be transferred out with the European Economic Area (EEA) at any time: <div style="text-align: center;">No</div> | | |
| Give Reason for transfer out with EEA: N/A | | |
| Nature of Information | | |
| Information Requested (specific details required): Interviews with patients will be recorded on a digital voice recorder. Signed consent forms. | | |

Intended use of data (include publications): The data will be analysed and the results written up in part fulfillment of the Doctorate in Clinical Psychology at the University of Edinburgh. It is hoped the results will inform service provision and be published in a peer-reviewed scientific journal.

Name of Person & Department responsible for the data gathering: Gillian Bailey, Clinical Psychology, Community Mental Health Team for Older Adults.

Detail how the shared data will be transferred, during storage and destruction

Participant recordings and transcripts will be coded to ensure anonymity. The recorded data will be stored on a password-protected digital recorder and transported in a locked case until it is transcribed. The recordings will be downloaded to a NHS Forth Valley laptop computer and transcribed. They will be backed up to the secured network drive. Transcripts from the interviews will be anonymised. Once transcribed the original recording will be deleted. The anonymised transcripts will be transferred to a password protected personal laptop. The patient code identifier information will be stored on a password protected secured network drive within NHS Forth Valley and consent forms will be stored in a locked filing cabinet within the Community Mental Health Team for Older Adults department.

Caldicott Guardian Details ("see over for appropriate Guardian")

| | |
|---|--|
| Name: | Dr Tracey Gillies |
| Position: | Caldicott Guardian/Medical Director |
| Organisation: | NHS Forth Valley |
| Address: | Carseview House Castle Business Park Stirling FK9 4SW |
| Tel. No. | 01786 457283 |
| Data Protection Registration No: | Z6175671 |

Please return this form to:

Information Governance Department
Central Supplies
Colquhoun Street
Stirling
FK8 7PX

Telephone NO: (01786) 433285

Fax No: (01786) 451156
(Non Secure)

Office Use Only

| | | | |
|--|------------|------------------------------|------------|
| Date Received – Information Governance | 19/12/2014 | Date Sent to Guardian: | 22/12/2014 |
| Form Checked By: | LALLEN | Date received from Guardian: | 05/1/15 |
| Date Checked: | 22/12/2014 | Copy sent to applicant: | 05/1/15 |
| Information Governance Approved: | YES NO* | Date sent: | |
| *If No: state reason: | | | |

Confidentiality Statement

For users of NHS patient data

Recipient's Declaration:

I declare that I understand and undertake to abide by the rule for confidentiality, security and release of data received from _____, as specified in points 1 - 7 on page 4 of this document.

Signature: Gillian Bailey

Date: 19/12/2014

Name: Gillian Bailey
(Print)

Caldicott Guardian's Declaration:

I declare that _____ (named above as the recipient of the data requested), is engaged in a reputable project and that the data requested can be entrusted to him/her in the knowledge that (s)he will conscientiously discharge his/her obligations in regard to confidentiality of the data, as stated in paragraph 1 - 7 on page 3 of this document. I am happy for him/her to receive this data.

Signature: _____
(on behalf of NHS Forth Valley)

22/12/14
Date:

Name: _____
(Print)

RULES OF CONFIDENTIALITY, SECURITY AND RELEASE OF INFORMATION

FOR USERS OF NHS NON ANONYMISED DATA

1. Data held by NHS Forth Valley on is registered under the Data Protection Act 1998 for the purposes of:
 - The provision and administration of patient care
 - Staff Administration
 - Research
 - Prevention and control of disease within the community

It cannot be used for any other purpose.
2. If the data received from NHS Forth Valley is to be held on computer or in manual records, the intended recipient of this request, or the organisation (s)he represents, should have an appropriate registration with the Office of the Information Commissioner. Details of the registration number should be entered on page 1 of this document. This will be verified prior to release of any information.
3. Data received from NHS Forth Valley should not be divulged to any person whose name is not specified as a 'co-user of data' nor used for any purpose other than that declared on page 1 of this document.
4. Proper security safeguards (e.g. encryption, password protected, Secure Mail Delivery, Double wrapped) will be applied during the transfer, use, storage and destruction upon completion of the work/project declared on page 1 to prevent any breach of confidentiality. Any misuse or loss of these data should be notified immediately to NHS Forth Valley's Data Protection Officer (email: linda.allen2@nhs.net, telephone 01796 433285).
5. Recipients should not attempt to access hospital case records using information supplied by *[details of supplying location]*, without the prior consent of the consultant in clinical charge of those patients. This applies regardless of whether the patient is currently in hospital or not.
6. No patient should be approached by a research worker as a result of information supplied by *[details of supply location]*, without prior consent of the consultant who was responsible for the care in the episode selected for research.
7. Any statistics or results of research based on data received from _____ should not be made available in a form which:
 - a) directly identifies individual data subjects
 - b) is not covered by the "intended use of data" clause specified on page 1

* For release to other NHS organisations of data relating to their own treated patients the authoriser will be the Medical Director/Caldicott Guardian. For release to Health Boards of data relating to their resident population the authoriser will be the Medical Director/Caldicott Guardian.





- Tell me about your experience of learning to live with dementia? (What has helped?)
- What do you think are the most important ways to learn to live with dementia? How did you discover (or create) them? |
- What helps you to manage your symptoms of dementia? What problems might you encounter?
- Who has been the most helpful to you during this time? How has he/she been helpful?
- Has any organisation been helpful? What did they help you with? How has it been helpful?
- What makes it difficult to live with dementia?
- What experiences during your life before you developed dementia can you think of that might have helped you live with dementia now?
- Are there any ways in which you have grown as a person since your diagnosis with dementia? Tell me about your strengths that you have discovered or developed. What do you most value about yourself now? What do others value in you?
- Tell me about how your views (and/or actions depending on topic and preceding responses) may have changed since you were diagnosed with dementia.
- How, if at all, have your thoughts and feelings about dementia changed since your diagnosis?
- What positive changes have occurred in your life since your diagnosis of dementia?
- Could you describe the most important lessons you have learned through experiencing dementia?
- What advice would you give to someone else who has recently found out they have dementia and are just beginning to learn how to live with it?

Ending questions

- Is there anything that you might not have thought about before that occurred to you during this interview?
- We are almost finished is there anything that you would like to add or anything you think I should know to understand dementia better?
- What are you doing with yourself for the rest of the day?

Appendix 11

| | | |
|---|--|---|
|  | |  |
| Demographics Data Sheet | | |
| Gender | | |
| <input type="checkbox"/> Male | | |
| <input type="checkbox"/> Female | | |
| Patient age | | |
| Type of dementia (if known) | | |
| Years since diagnosis | | |
| Patient marital status | | |
| <input type="checkbox"/> single (never Married) | | |
| <input type="checkbox"/> married | | |
| <input type="checkbox"/> partnered (other than married) | | |
| <input type="checkbox"/> separated/ Divorced | | |
| <input type="checkbox"/> widowed | | |
| Patient highest academic achievement | | |
| <input type="checkbox"/> primary school | | |
| <input type="checkbox"/> high school | | |
| <input type="checkbox"/> trade or technical certificate | | |
| <input type="checkbox"/> college diploma | | |
| <input type="checkbox"/> university degree | | |
| <input type="checkbox"/> post graduate degree | | |
| <input type="checkbox"/> other | | |
| Patient living arrangements | | |
| <input type="checkbox"/> living at home (supported by family/ carer or partner) | | |
| <input type="checkbox"/> living with family/carers but not own home | | |
| <input type="checkbox"/> living alone | | |
| <input type="checkbox"/> living in sheltered accommodation | | |
| <input type="checkbox"/> Other | | |
| Location | | |
| <input type="checkbox"/> urban | | |
| <input type="checkbox"/> rural | | |

Page 1 of 2

Exploring Resilience in People with Dementia: a Qualitative StudyVersion 1 9/11/14



Ethnicity

White

- ☐ British
 - ☐ Any other white background (please specify)
-

Black

- ☐ British
 - ☐ Caribbean
 - ☐ African
 - ☐ Any other black background (please specify)
-

Asian

- ☐ British
 - ☐ Indian
 - ☐ Pakistani
 - ☐ Bangladeshi
 - ☐ Any other Asian background (please specify)
-

Chinese

- ☐ British
 - ☐ Chinese
 - ☐ Any other Chinese background (please specify)
-

Mixed

- ☐ White & Black Caribbean
 - ☐ White & Black African
 - ☐ White & Asian
 - ☐ White & Chinese
 - ☐ Any other mixed background (please specify)
-

Other ethnic group

- ☐ Other ethnic group not above (please specify)
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